Preliminary Draft

CHRONIC/LONG TERM CARE SERVICES

DISTRICT OF COLUMBIA STATE HEALTH SYSTEMS PLAN

State Health Planning and
Development Agency
District of Columbia
Department of Health

CHRONIC/LONG TERM CARE SERVICES

TABLE OF CONTENTS

TITLE		PAGE
I.	CHRONIC/LONG TERM CARE SERVICES…….	1
II.	NURSING FACILITIES, OTHER INSTITUTIONAL, COMMUNITY BASE RESIDENTIAL FACILITIES.…….	15
III.	HOME HEALTH SERVICES…….	35
IV.	ADULT DAY CARE SERVICES……	47
V.	END OF LIFE SERVICES……..	59
VI.	APPENDICES……	66

CHRONIC/LONG TERM CARE SERVICES

I. INTRODUCTION

Long-term care refers to a "comprehensive range of health, social and support services coordinated to meet the continuing needs of persons who are aged, chronically ill or disabled. Services may be continuous or intermittent, but are delivered for a sustained period to individuals who have a demonstrated need, usually measured by some 'index' of functional dependency" (AARP 1999).[1] An index that is commonly used relates to an individual's need for assistance with activities of daily living (ADLs) such as eating, dressing, and bathing, and/or instrumental activities of daily living (IADLs) such as managing money, housekeeping, and shopping. Implicit in this definition of long-term care is that persons requiring assistance span all ages, services are interdisciplinary in nature representing a continuum of both medical and social care, and care can take place in various settings including the home, community, and institution.

II. BACKGROUND AND TRENDS

A. Long Term Care Users

Although the majority of long-term care users are elderly, persons of all ages with a variety of physical and mental conditions may also need some form of long-term care. These persons include developmentally disabled children and adults, the mentally retarded, the mentally ill, and persons who have a physical disability

Nationwide, it is estimated that 450,000 children ages 5 to 17 living in the community have difficulty performing some ADLs and are in need of long-term care assistance. Between 9 and 13 percent of children ages 9 to 17 have serious emotional disturbances with substantial functional impairment, and between 5 and 9 percent have extreme functional impairment (DHHS, SAMHSA 1998).[2]

Over 9 million adults (aged 18 and over) received long-term care assistance either in community settings or in institutional settings in 1994. Over 80 percent of adults receiving long-term care reside in the community, rather than institutions. Of this 80 percent, about a quarter, have severe impairments. Over 90 percent of the 1.6 million adults residing in a nursing home in 1994, were over the age of 65 (Tilly, Goldenson & Kasten 2001).[3]

---

[1] AARP Public Policy Agenda, 1999.

[2] *America's Children: Key National Indicators of Well-being*, Federal Interagency Forum on Child and Family Statistics, 1999; and R.M. Friedman, et al., "Prevalence of Serious Emotional Disturbance: An Update," *Mental Health*, United States, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services, 1998.

[3] Jane Tilly, Susan Goldenson, and Jessica Kasten. *Long-Term Care: Consumers, Providers, and Financing A Chart Book*, Urban Institute, March 2001.

National estimates of the number of persons with MR/DD show that the majority is under the age of 17 (59%), though persons aged 17 to 64 constitute 38 percent of the overall MR/DD population. The number of younger persons with MR/DD living in large state institutions has dramatically declined over the past two decades. More than half of persons with MR/DD living in residential settings were in small group residences (1 to 6 residents) in 1998, while nearly a quarter lived in settings with 16 or more residents (Braddock et al., 2000).[4]

The number of non-institutionalized, disabled persons living in the District of Columbia resembles the national average by proportion of the overall population and relative to age (see **Table 1**). In the District of Columbia, approximately 15 percent of its residential population aged 5 and older has some type of disability (U.S. Census Bureau 2000).[5] Of this population, the number of persons aged 65 and older with a disability is more than three times the number of persons aged 21 to 64 and more than five times the number of those aged 5 to 20 years.

Table 1. Disability Status of Non-Institutionalized Persons in the District of Columbia Compared to the United States, 2000

Age	Population	Number of Persons with a Disability	Percent with a Disability	Percent Employed
District of Columbia				
5-20	98,893	7,128	7.2%	N/A
21-64	337,324	40,679	12.1%	46.3%
65+	65,326	25,217	38.6%	N/A
Total (age 5+)	501,543	73,024	14.6%	
United States				
5-20	63,402,504	4,245,070	6.7%	N/A
21-64	157,521,282	22,189,889	14.1%	48.7%
65+	33,079,053	13,524,057	40.9%	N/A
Total (age 5+)	254,002,839	39,959,016	15.7%	

Note: The Census Bureau defines disability as a long-lasting physical, mental, or emotional condition that can make it difficult for a person to do activities such as walking, climbing stairs, dressing, bathing, learning, or remembering. The condition can also impede a person from being able to go outside the home alone or to work at a job or business.

Source: U.S. Census Bureau, Census 2000 Supplementary Survey

[4] David Braddock et al. *The State of the States in Developmental Disabilities: 2000 Study Summary*, Published by the Department of Disability and Human Development, University of Illinois at Chicago.

[5] Disability is broadly defined by the U.S. Census Bureau to be a long-lasting physical, mental, or emotional condition. Persons included in the total non-institutionalized population as having a disability includes many individuals in the workforce and may overestimate the number of long-term care users with health-related needs.

There has been an increase in both the number of elderly and non-elderly persons with long-term care needs over the past few decades, a trend that is likely to continue. Growth due to the aging of the baby boom generation, in particular, will have a large impact on resource supply and utilization. Medical and other technological advances allow children and young adults to survive longer with their impairments than in previous times. These continuing improvements are likely to result in a growing demand for long-term care services.

In addition to an increase in the volume of those likely to demand long-term care, population projections indicate that significant socio-demographic changes (e.g., age, racial and ethnic mix, and level of education) among the chronically-ill and disabled as well as their supports, will take place over time. These changes will impact both the supply of and demand for long-term care services provided in the home, community, and institution.

B. Long-term Care Services Continuum

The array of health, mental health, and social services spanning all level of care for persons with long-term care needs is commonly referred to as a "continuum of care." The continuum includes services representing various levels of intensity that an individual would access as the needs of the individual change. The continuum of long-term care includes: extended care, acute care, ambulatory care, home care, outreach, wellness and health promotion, and housing.

C. Long Term Care Services in the District of Columbia

The major types of health services that exist in the District of Columbia's long-term care continuum for which resource planning is essential are: 1) Skilled Nursing and Community Residential Care; 2) Home Health Care; 3) End-of-Life; and 4) Medically Supervised Day Care. Each service type is described separately in other subsections in this chapter. The previously mentioned service types relate to most of the District of Columbia's long-term care populations.

D. Service Definitions

1. Long Term Care Facility

Long-term care facilities are institutions that provide skilled nursing care and related services for individuals who require medical, nursing, rehabilitation, or subacute care services. These facilities include nursing homes, hospital-based facilities, and intermediate care facilities for the mentally retarded (ICF/MRs).

2. Congregate Living Setting

Congregate living settings include small ICF/MRs and community residential care facilities (CRFs) such as, board and care homes and supported living. There is an array of CRFs classified under Chapter 34 and 35 of Title 22 of the District of Columbia Municipal Code, for the elderly

and for the mentally retarded. These facilities provide a level of health care in a safe, hygienic, protective sheltered living arrangement for one or more individuals who are not related by blood or marriage to the Residence Director.

The level of health care is designed for individuals who desire or require supervision or assistance within a protective environment because of physical, mental, familial or social circumstances. There are also community residential facilities for the mentally ill, classified under chapter 38 of the municipal code, which house individuals who are 18 and older with a principle diagnosis of mental illness and who require 24-hour supervision, personal assistance, lodging and meals.

Board and care homes are non-medical facilities that provide limited assistance to residents with functional limitations. Historically, they have predominantly provided care to persons with mental illnesses or developmental disabilities but are increasingly serving persons with physical impairments. The District of Columbia offers State Supplemental Payments to the federal Supplemental Security Income (SSI) to help subsidize the cost of board and care homes.

New assisted living regulations (DC Law 13-127) that set minimum standards for CRFs previously covered under Chapter 34 of Title 22 of the District of Columbia Municipal Regulations, will be drafted in year 2003 and will provide the District of Columbia's elderly population with options for assisted living.

3. Home Health Care

Home health care refers to the in-home provision of skilled health services such as nursing, home health aide, occupational, physical, or speech therapy, and medical social work. Home health care is provided to persons to promote, maintain, or restore health and to maximize their independence (Kane, Ouslander & Abrass 1999).[6] This service is appropriate for all age groups, but the most intense users of home health service are the elderly. Home health care is often supplemented by home care services such as homemaker, non-skilled personal care, companion, and home-delivered meals.

4. Adult Day Care

Adult day care (ADC) programs provide health and social services in a group setting to individuals with physical, emotional, or cognitive disabilities. Services are provided in a protective setting during any part of the day but less than 24-hour care. There are two basic models for ADC programs: social and medical. The medical model, often referred to as day treatment or day health care, is therapeutically oriented offering health maintenance and rehabilitative services to functionally impaired individuals. Services typically include nursing,

[6] Robert L. Kane, Joseph G. Ouslander, and Itamar B. Abrass. *Essentials of Clinical Geriatrics.* Fourth Edition, McGraw-Hill; 1999.

social services, personal care, rehabilitation therapies, meals, counseling, and transportation. The social model includes therapy that enhances the patient's cognitive abilities as well as recreational therapy and exercise.

Medically supervised day care programs care for the frail elderly, other physically disabled adults, persons with mental illness and the developmentally disabled. However, the focus or specialty of each program is dependent upon the needs of the population to be served. Subsequently, not all day care programs for the mentally ill and developmentally disabled are medical. Adult day care programs, many of which are based in the community, focus on health maintenance and the prevention or delay of further deterioration.

5. End-of-Life

End-of-Life (EOL) services are defined by the National Hospice and Palliative Care Organization as pain management, palliative care and hospice services for individuals who have been determined by a physician to have a terminal illness. Within end-of-life care, there are two major service types:

(1) Hospice Care: "Services focused on the provision of palliative care or interventions aimed at reducing or alleviating pain and other physical and psychosocial symptoms of terminal illness. With the goal of maximizing the quality of life, hospice services keep the patient comfortable in his or her own home or in a hospice inpatient unit with a home-like environment."

(2) Palliative Care: "An intervention that seeks to address not only physical pain, but also emotional, social and spiritual pain to achieve the 'best possible quality of life for patients and their families.' Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness or disease process (NHPCO 2001).[7]

6. Case Management

Case Management is defined by the Case Management Society of America as a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality cost effective outcomes (Case Management Society of America).

According to the Development Disability Quality Coalition, individuals with developmental disabilities, as well as frail adults over the age of 65, often have tenuous

[7] Taken from the NHPCO website at www.nhpco.org.

and incomplete ties to the health and mental health systems. Case management services, assist in improving these ties.

D. Overview of the Existing System

A description of the District of Columbia's administrative oversight for major health-related long-term care services can be found in **Appendix A**.

In District of Columbia, like the rest of the U.S. health system, long-term care is a collection of services that has no single financing or delivery structure. Just as each individual requiring long-term care has a unique set of circumstances, each state and local community has, over time, developed its own combination of service resources, funding streams, and organization.

The major sources of long term care financing in order of level of support are Medicaid, out-of-pocket, Medicare, private health insurance, and other. Medicaid is a joint federal and state program of medical assistance that includes coverage of categorical long-term care services for eligible populations. Medicaid spending for long-term care supports some nursing facility, ICF/MR, and home and community-based care.

Medicare was designed to finance medical expenses associated with acute care fore the elderly and disabled. Medicare coverage limits the duration and frequency of care provided to beneficiaries and does not include critical long-term care assistance, such as custodial care or pharmaceutical benefits. Medicare covers short-stay care in skilled nursing facilities and home health care on a limited basis.

Medigap is a voluntary private insurance product purchased by some Medicare beneficiaries to help fill the gaps in Medicare coverage (i.e., deductibles, co-payments, outpatient services, pharmaceuticals, etc.), but does not finance extended long-term care facility stays or home and community-based needs.

Private long-term care insurance is largely unavailable or inappropriate to meet the needs of the vast majority; nationally less than 10 percent of the elderly and an even lower percentage of near-elderly individuals have purchased long-term care insurance to date (GAO 1998).[8]

Family members and other informal supports are the backbone of the long-term care system and provide the bulk of all long-term care for the disabled and chronically ill. Current trends of reduced hospital admissions, shortened hospital stays, increased use of outpatient services, and increased biomedical advances will continue to have an impact on the long-term care industry, particularly for home and community-based care provided on an informal basis. Despite the fact that the vast majority of individuals in need of long-term care reside in the community, nearly 70 percent of public funding for long-term care currently goes to institutional care. The District of

[8] GAO (1998). *Long-Term Care: Baby Boom Generation Presents Financing Challenges.*

Columbia's long-term care system, like that of other states, is faced with the challenges associated with providing comprehensive care to a growing long-term care population with a diverse set of needs.

The Medical Assistance Administration (MAA) is the largest funding source of personal care services in the District of Columbia. The District of Columbia operates home health services program under its Medicaid Plan: Personal Care Aide Services/Home Health Aide Services. This program serves approximately 1,700 consumers, annually. The Personal Care Aide Services Program is limited to eight hours per day; however with the elderly waiver program these services can be extended depending upon need for up to 16 hours per day.

To supplement its personal assistance service programs, the District of Columbia operates two Medicaid Home and Community-Based Waivers: a waiver that serves individuals over age 65, and a waiver for adults with mental retardation and developmental disabilities. The services offered under the waivers have fewer restrictions on the number of hours of service that can be provided. The main requirement is that the cost to administer HCBS shall not exceed the cost for similar services if delivered in a nursing facility.

Additional personal assistance services, funded by social services block grants, are currently available on a limited basis through Adult Protective Services (APS) and two programs administered by the Office on Aging. The APS Homemaker Services Program served 151 people in 1996.[9] While there are no prescribed limits on the number of hours of service that can be provided in this program, the number of individuals served and the fact that the total costs for these services are capped at $393,000 per year, indicate that individuals served in this program are receiving approximately 5-10 hours of service per week.[10] Both of the programs offered through the Office on Aging are limited to individuals 65 and older, and services must be provided in the home. The larger of the two programs, serving 553 individuals, limits services to six hours per week. The other program, serving 182 individuals, does not limit hours of service, but limits eligibility to individuals diagnosed with Alzheimer's disease who live alone.

In 1981, the Office on Aging established an Assessment and Case Management Program for frail residents age 60 and older who are experiencing difficulty in carrying out the activities of daily living and considered to be at risk of institutionalization. The case management team consists of service coordinators and nurses who assess the needs of individuals referred for services and develop a care plan to meet their unique needs. Case managers coordinate and arrange for services using both formal and informal resources. Increased access to care management could be a critical step to adequately addressing the preventive, habilitative, rehabilitative, and health maintenance needs of its residents.

[9] "Abuse, Neglect, and Exploitation," District of Columbia Government Department of Human Services Family Services Administration Adult Protective Services Program Annual Report, Fiscal Year 1999 (hereinafter "APS Annual Report").

[10] APS Annual Report. Given 151 consumers and an hourly rate of $10.50, each consumer received an average of 10 hours of service/week for 6 months, or 5 hours of service/week for the entire year.

District residents who wish to receive Medicaid reimbursements for services are assessed through a quality improvement organization (QIO) - Delmarva - and a determination is made as to whether they meet a nursing level of care. Delmarva is the peer review organization for all Medicaid eligible persons who must obtain a nursing level of care to obtain admittance to a nursing facility. The assessment team consists of physicians and nurses. One of their major functions is to review, the appropriateness of the level and type of care that individuals receive after they are placed and receive services.

E. Significant and Emerging Issues

Long-term care (LTC) reform efforts nationwide have largely focused on developing continuity of care within the care continuum using mechanisms that broker services in a coordinated fashion to facilitate navigation by individuals of all ages, across programs, agencies, and funding streams. In doing so, states are ensuring that the LTC system is a responsive one in which available funds will follow the person to the most appropriate and cost-effective setting of their choice.

1. Institutional Bias

The District of Columbia currently relies for the most part on institutional care. The primary reason this persists is the lack of a viable Home and Community Based Services (HCBS) program. In addition, the reimbursement system favors nursing home care. As a result, institutional levels of care have become the default in treating individuals with long-term care needs. In fiscal year 2000, 96 percent of Medicaid spending on long-term care supported institutional care and only four percent supported home and community-based services (**Table 2**). Nursing facilities account for the majority (56 percent) of institutional spending. While the last large ICF/MR institution in the District of Columbia, Forest Haven, closed in 1991, the District of Columbia still serves the MR/DD population in smaller, community-based ICF/MRs. Institutional settings continue to be an important aspect of care for the aged, physically disabled, and mentally ill populations.

Table 2. DC Medicaid Long-Term Care Expenditures in FY 2000

	Expenditures (in thousands)	% of LTC Spending
Home and Community-Based Services		
Personal Care Attendants	6,889	3%
MR/DD Waiver	226	0%
Elderly Waiver	919	0%
Residential Treatment	1,637	1%
Subtotal	9,672	4%

Institutional Services		
Nursing Facility care	142,861	56%
ICF/MR	76,227	30%
Day Treatment	24,575	10%
Subtotal	243,663	96%
Total	253,335	100%

Source: Medical Assistance Administration, District of Columbia, Department of Health

The recent Olmstead court ruling provides an even greater incentive for states to support community-based residential options. In Olmstead vs. L.C. (1999), the Supreme Court recently upheld a lower court ruling that, to avoid violating the ADA, requires states to place persons with disabilities in community settings instead of institutions if community placement is appropriate, the transfer to the community is not opposed by the individual in question, and placement can be accommodated given the resources available (Carelli, 1999).

2. Barriers to Accessing the LTC System

The major barriers to the viability of HCBS in the District of Columbia include in many instances administrative complexity, shortage of home care aids, and a need for consumer education in reference to the availability of all programs. In addition, the processing time for Medicaid eligibility for the elderly and persons with disabilities is particularly problematic for individuals in the midst of a care-giving crisis.

3. Incomplete Continuum of Care

Home and community-based services are limited in the District of Columbia because many services are either: (1) not covered under the state plan or a waiver, or (2) reimbursement rates or structures are not sufficient to attract providers. The lack of a continuum of care limits the availability of HCBS as an alternative to an institution to a minority of individuals whose needs are met by the relatively narrow range of accessible services. This situation is particularly problematic for younger adults with physical disabilities who only have access to the Personal Care Aide program. The Medical Assistance Administration (MAA) recently received approval from CMS and the District of Columbia City Council regarding a Waiver amendment to allow young adults with physical disabilities to access services under the Elderly Waiver. Implementation by MAA is expected in the year 2003.

4. Insufficient Community Service Infrastructure

In order to increase home and community-based options for long-term care users, adequate infrastructure needs to be in place. The necessary infrastructure includes dedicated administrative and program staff, a case management network, information technology support, appropriate financing and accounting mechanisms, quality assurance protocols, and affordable housing. The case management network would ensure that the appropriate amount and type of service is

provided for each individual. The development of a long-term care information system is critical to the District of Columbia's success in ensuring proper levels of service utilization at appropriate costs. Information technology can enhance the quality assurance process and heighten the ability to meet federal and local reporting requirements. In addition, better access to databases will afford case managers with the flexibility to provide services in cost-effective ways and enhance their ability to monitor cost and quality.

The supply of affordable housing remains to be an area of concern in the District of Columbia and impacts the ability of persons who are receiving care within traditional institutions to transition into home and community-based settings. The District of Columbia is now beginning to coordinate planning in this regard.

5. Diminished Flexibility in "Family-Centered" Service Delivery

Current financial and regulatory mechanisms impede family-centered care principles. In a family-centered care delivery system, the individual and his or her family are at the center of care delivery and services are tailored to the needs of that particular family. In this way, services are designed to support rather than replace informal care networks. The new focus should be to promote outcome-based measures of quality, allow consumers to set quality standards, and allow providers greater flexibility with regard to how they achieve these quality outcomes.

It has been suggested that one of the tools to address institutional bias, barriers, to accessing the system, incomplete continuum of care, insufficient community service infrastructure, and diminished flexibility in "family centered" service delivery is the establishment of a clinical case management and disease management program that is based on national standards for case management quality and provided by clinicians. Disease management is defined by the Disease Management is defined by the Disease Management Associations of America as a system of coordinated healthcare interventions and communications for populations with conditions in which patient self-care efforts are significant.

Disease management:

(1) Supports the physician or practitioner/patient relationship and plan of care;
(2) Emphasizes prevention or exacerbation and complications utilizing evidence-base practice guidelines and patient empowerment strategies, and
(3) Evaluates clinical, humanistic, and economic outcomes on an ongoing basis with the goal of improving overall health.

III. SUMMARY RESOURCE INVENTORY AND HISTORICAL UTILIZATION

A. Nursing Facilities

The District of Columbia's long term-care delivery system includes 21 private nursing facilities

with a total of 3,097 beds.[11] There are approximately 3,250 individuals in the District of Columbia receiving Medicaid-reimbursed facility care. Nineteen percent of these residents are under the age of 65 years and 81 percent are age 65 years and older. Of the total Medicaid-funded residents from the District of Columbia, 383 reside in nursing facilities in Virginia, Maryland, and Delaware. Occupancy rates are relatively high at 92 percent.

Medicaid reimbursement for nursing homes is in the form a prospective payment. This form of payment acts as a disincentive for providers to locate consumers to lower levels of care. Based on a report by the Urban Institute that recommended adjusting the nursing facility reimbursement system to a case-mix system to provide less incentive for nursing facilities to serve individuals with fewer impairments, MAA recently awarded a contract for the development of a case mix system. In FY 2000, Medicaid expenditures for nursing facility bed days totaled $140,799,832 for 3,837 beneficiaries with chronic and functional disabilities.

ICF/MRs are licensed facilities approved for Medicaid reimbursement that provide specialized services for individuals with mental retardation or related conditions. Class action litigation was filed in 1976 (Evans v. Washington) resulting in a court order requiring that the District of Columbia to develop community-based alternatives to institutions.[12] Currently, there are 129 ICF/MRs in the District of Columbia, most of which are privately-owned, non-profit facilities. An ever-fluctuating number of different Medicaid providers; however licensed beds remain relatively static at 851. The majority of ICF/MRs in DC are small free-standing facilities with an average of 8 licensed beds per facility. In 1998, the average reimbursement per day for residential services in the District of Columbia was $243. In 2000, the average per capita spending on individuals in private facilities was $87,216.

B. Home Health Care

Home health care in the District of Columbia is predominantly delivered by freestanding or hospital-based agencies under various types of sponsorship. There are currently 20 home health agencies operating in the District of Columbia, according to the Health Regulation Administration. In 1998, Medicare's home health program served just over 7,000 people in the District of Columbia, with spending equal to $20.6 million. In 1998, the District of Columbia's Medicaid Home Health program served almost 3,000 people, with expenditures approximately $12.4 million.

C. End of Life Services

Growth of hospice services in the District of Columbia has been minimal. In 1977, there were three hospices. Today, the District of Columbia has two hospices, which are Medicare certified.

[11] The District of Columbia also has two federal nursing facilities.

[12] David Braddock et al. *The State of the States in Developmental Disabilities: 2000 Study Summary.* Published by the Department of Disability and Human Development, University of Illinois at Chicago.

These facilities serve an average of 350 people per year. Medicare is the primary payment source (63.5 percent), while Medicaid pays 7.8 percent. The current general Inpatient Care Medicare rate is $ 453.04 per day.

D. Medically Supervised Day Care

The District of Columbia currently has six Adult Day Care facilities that are licensed under Medicaid. Community-based institutions primarily deliver Adult Day Care services. The majority of facilities provide services for an average of 60 people per day. Three main types of population are served: developmentally disabled adults, functionally impaired elderly and individuals with substance abuse problems. There is currently no federal regulation tied to Adult Day Care and Medicaid funding represents only 50 percent of the total reimbursement for these services in the District of Columbia.

E. Community Residential Facilities

Currently, there are 579 beds under Chapter 34 community residential facilities (CRFs) in the District of Columbia. A total of 33 Community residence facilities are licensed under Chapter 34 of Title 22 of the DC Municipal Regulations.

Chapter 38 regulates facilities for individuals with mental illness as a primary diagnosis. Currently, the District of Columbia, Department or Mental Health has 106 providers who operate 200 facilities with 1,024 licensed beds under Chapter 38.

Chapter 35 of the code regulates CRFs and ICF/MRs for the MR/DD population. There are 129 Medicaid-certified facilities (ICF/MRs), with 851 licensed beds under Chapter 35.

The total number of CRF facilities is 162, including those that are not certified by Medicaid (33). This represents a decrease from 216 facilities in 1998. In addition, the total number of beds decreased from 1,724 in 1998 to 1,020 beds in 2002.[13]

One of the fastest growing residential services in the country is “assisted living facilities” for the elderly. The District has recognized this growth and is moving to implement the Assisted Living Residence Regulatory Act of 2000. The Act establishes a licensure and inspection system.

IV. GOALS AND OBJECTIVES FOR LONG TERM CARE

Goal 1: Develop a flexible tracking system for entire long-term care delivery system.

Objectives:

[13] DC Health Regulation Administration and Harrington, et al (1999).

1.1 Integrate information systems to support one client/patient record that can be accessed among multiple providers, programs and payers.

1.2 Develop a standardized tool to better monitor changes in quality and expenditures in long-term care settings.

1.3. Review licensure requirements that will allow better tracking of clients/patients.

Goal 2: Establish a long-term care consumer advocacy, education and counseling program.

Objectives:

2.1 Develop partnerships with consumers and their advocates

2.2 Support the creation of a cross-disability consumer advocacy group

Goal 3: Increase coordination of care and decrease multiple points of entry into the system.

Objectives:

3.1 Create a Resource Center to act as a single point of entry by providing long-term care options, such as counseling, assessment, eligibility determination, and re-determinations.
3.2 Develop a plan, which includes case managers to assist individuals and their families, nursing facilities, home health agencies, hospitals, providers, community agencies, and other entities to better navigate the system to access needed services through the Resource Center.

Goal 4: Integrate acute and long-term care services to develop a more comprehensive health delivery system.

Objectives:

4.1 Establish a care management program that will link acute and chronic care service sectors and meet national care management standards.
4.2 Establish a process for case managers to facilitate the coordination of comprehensive health care services.
4.3 Establish guidelines for the development of individualized care plans that outline measurable goals and provide the basis for evaluation of services provided.

4.4 Develop a standardized tool for measuring the standards established.
4.5 Develop and/or review care planning guidelines and criteria for the acute and chronic care service sectors.
4.6 Evaluate the effectiveness of the delivery system.[14]
4.7 Determine the feasibility of developing a public/private partnership to integrate the various long-term care funding streams.
4.8 Determine the feasibility of a Medicaid waiver initiative for managed long-term care services.

Goal 5: Create a funding mechanism for implementing long-term care reform initiatives.

5.1 Develop a strategy for approaching the Center for Medicare and Medicaid Services (CMS, formerly known as HCFA).
5.2 Expand home and community-based care through exploration of additional Medicaid waivers.
5.3 Develop a program to promote and educate consumers about private long-term care insurance.

[14] Robyn I. Stone. *Long Term Care for the Disabled Elderly: Current Policy, Emerging Trends and Implications for the 21st Century*. Available at http://www.milbank.org.

NURSING FACILITIES, OTHER INSTITUTIONAL CARE, COMMUNITY-BASED RESIDENTIAL FACILITIES

I. INTRODUCTION

Several options exist along the continuum of long-term care residential services. These facilities provide assistance in a variety of settings from residential to institutional and assist individuals with varied functional needs. These options include, Nursing Facilities, Intermediate Care Facilities for the Mentally Retarded (ICF/MRs),
Assisted Living Facilities (ALFs), and Community-based Residential Facilities (CRFs).

II. BACKGROUND AND TRENDS

A. History

Nursing facilities typically care for individuals with chronic conditions and disabilities who have physical and/or mental impairments, which have been determined by a licensed provider that whose continuing care cannot be provided in a home or outpatient setting. Historically, the elderly (65 and over) have been the primary users of nursing facility care as these individuals frequently have multiple conditions which are related to, or aggravated by, aging and can no longer maintain an independent lifestyle. Although the pediatric (0 - 19) and younger adult populations (20 - 64) do not utilize nursing facility services at a rate as high as the elderly, younger persons with disabilities do make up about 8 percent of the institutionalized population nationwide.[15]

Nursing facilities usually offer skilled nursing care which is viewed as the most intensive level of care provided on a continuous basis outside of a hospital as it involves the direct provision or supervision of medical care by a registered nurse on a daily basis. Individuals in need of skilled care may require services such as oxygen therapy, tube feedings, and/or intravenous drug therapy. Due to the staff time as well as the level of skill required to care for persons needing skilled care, the cost of this care is often higher than less intensive levels of care and is generally reimbursed at a higher rate.

As part of the amendments to the Social Security Act in 1950, the federal government required states to establish licensing requirements for nursing facilities that received payments from the state. However, it was not until the establishment of Medicare, which covers skilled nursing services, and Medicaid, which covers custodial nursing services, in 1965, that the modern NF industry began to evolve. The new coverage offered by Medicare for skilled and custodial nursing care created a surge in the supply of nursing homes. The presence of reliable and

[15] Spector, W., J. Fleishman, L. Pezzin, et.al. (2000). "The Characteristics of Long-Term Care Users." *AHRQ Research Report*, August 2000 (Publication Number 00-0049).

lucrative payment sources provided the nursing home industry with the incentive to expand to meet the new demand.

Rapid growth and relatively limited regulation of nursing facilities led to a series of widespread financial and quality-of-care scandals in the 1970s and early 1980s; State governments, concerned about the rapid growth in the use of nursing facility services--and hence in Medicaid expenditures--established Certificate of Need (CON) programs and/or moratoria on the construction of new nursing home beds. As of 1998, 44 states still regulated NF supply through one or both of these methods.[16]

B. Financing Issues

District nursing facilities are among the most expensive in the nation. The average Medicaid per diem for District NFs was almost double the national average. The only state with a greater Medicaid per diem in 1998 was Alaska (at $253). On the other hand, Medicare SNF payments in the District of Columbia are only 15 percent greater than the national average, in part because the Medicare Prospective Payment System (PPS) has eliminated some of the geographic variation in prices. **Table 1** displays the per diem costs for the range of residential options in the District of Columbia.

Table 1. Average Reimbursement Per Day for Residential Services in the District of Columbia and Nationwide, 1998

Service	District	National
Medicaid NF[a]	$180	$96
Medicare SNF[b]	$281	$245
Medicaid ICF/MR[c]	$243	$222
ALF[d]	N/A	$66
CRF	N/A	N/A

Sources: AARP, Across the States: Profiles of LTC Systems, 2000; Citro, J. and Hermanson, S. (1999, March) Public Policy Institute, AARP, Washington, DC.

(a) Indicates mean Medicaid reimbursement per diem in 1998. Note that NF users who are not Medicaid beneficiaries may face higher prices.
(b) Indicates mean Medicare reimbursement per diem in 1998. Note that this excludes any beneficiary coinsurance payments (which begin after the 20th day of a SNF stay).
(c) Indicates mean Medicaid reimbursement per diem in 1998.
(d) Indicates mean per diem amount charged by facilities in 1997-1998. One industry estimate (AHCA, Sourcebook) found that assisted living facilities report charging approximately $59 per day ($1,807/month). Another estimate (ALFA, Overview) found an average daily rate of $66 for private studio apartments ($2,030/month).

[16] Harrington, et.al. (1999).

Medicaid is the predominate payer for NF services in the District of Columbia. Every non-federal nursing facility in the District of Columbia participates in the Medicaid program.[17] **Table 2** gives the distribution of primary payer for NF services in the District of Columbia and nationwide, from three different sources.

Table 2. Primary Payer for NF Services in DC and Nationwide in 1999

	District			National		
Source	Medicare	Medicaid	Other*	Medicare	Medicaid	Other*
AARP[a]	6%	85%	9%	9%	68%	24%
AHCA[b]	7.1%	84.3%	8.6%	8.7%	67.7%	23.5%
State Data Book[c]	7.2%	81.3%	11.5%	8.6%	67.7%	23.7%

*Other represents out-of-pocket, private long-term care insurance, and other public and private sources.
(a) AARP (2000). Across the States: Profiles of LTC Systems, 2000.
(b) American Health Care Association (2001). Health Services Research and Evaluation.
(c) Harrington, et. al. (1999). 1998 State Data Book on LTC Programs and Market Characteristics.

The District of Columbia departs significantly from national trends in terms of NF financing. Medicaid, though also the most important payer nationally, pays for more than 80 percent of the District of Columbia's nursing home costs. Out-of-pocket and other sources of funding are much less important as payers in the District than they are nationwide. According to HCIA-Sachs (2001), about 90 percent of NF residents in the District of Columbia are Medicaid beneficiaries.[18] Medicaid beneficiaries seem to be the most intensive users of NF services, accounting for more than 95 percent of all NF days in 1998. Nationwide, Medicaid beneficiaries accounted for only 73 percent of NF days.

Because Medicaid is the largest payer for NF care, the District of Columbia's Medicaid policies exert significant influence on NFs particularly through reimbursement policy. The Medicaid reimbursement rate for NFs is prospective, but is based on facility-specific costs reported in 1995 (and adjusted for inflation using the Medicare Market Basket). Reimbursement is divided into three cost areas:

Nursing and patient care costs, including ancillary services (limited to 100 percent of the median reported amount);

Routine and support costs (limited to 100 percent of the median reported amount); and

Capital costs (no limit).

The median caps are calculated separately for hospital-based and freestanding facilities.

[17] All facilities except Jeanne Jugan also participate in Medicare.

[18] HCIA-Sachs, LLC and Arthur Andersen, LLP (2001). *The Guide to the Nursing Home Industry, 2001* Baltimore, MD: HCIA-Sachs, LLC.

The District of Columbia Medical Assistance Administration is interested in implementing a case-mix approach to reimbursement that would take into account patient characteristics in determining a prospective payment rate.

C. Financial Trends

1. Changes in Medicare Reimbursement Policy

As part of the Balanced Budget Act of 1997 (BBA), the Center for Medicare and Medicaid Services (CMS, formerly HCFA) established a prospective payment system (PPS) for skilled nursing services. The PPS reimburses service providers a fixed amount per day for a given service regardless of the costs incurred in provision of services.
Although the average nursing home derives only modest revenue from the Medicare program (about 13 percent), the impact of the BBA was far-reaching for a number of reasons. First, most nursing homes did not have very high profit margins to begin with; HCIA-Sachs (2001) report that the median profit margin in 1998 was 2.85 percent.

D. Quality Issues

The following table compares the District with the nation as a whole on several measures of resident health and outcomes.

Table 3. Indirect Measures of Quality of NF Resident Care, DC and National, 2000-2001

Percentage of residents exhibiting...	DC	US
Physical restraints	5%	9%
Pressure (bed) sores	13%	8%
Unplanned weight change	7%	7%

Source: HCFA, Nursing Home Compare

The amount of care provided by employees at District nursing homes is slightly greater than the national average. **Table 4** presents hours of care per resident by three categories of caregiver for the District of Columbia and nationwide.

Table 4. Hours of Care per Resident, by Caregiver Category, DC and National, 2000-2001

	RN hours per resident day	LPN/LVN hours per resident day	CNA hours per resident day	Total care hours per resident day
District	0.5	0.9	2.6	4.0
National Avg.	0.5	0.9	2.4	3.8

Source: CMS, Nursing Home Compare
Note: Registered Nurse (RN), Licensed Practical Nurse (LPN), Licensed Vocational Nurse (LVN), Certified Nursing Aide (CNA).

The District of Columbia is currently in the process of reviewing of regulatory standards for nursing facilities. The following are the basic premise of these staffing standards, which were adopted in 2002:

- Each NF must provide 24-hour licensed nursing services sufficient to meet the nursing needs of its residents.

- Each NF must employ an RN for at least 8 hours a day, 7 days a week.

In response to concerns about the quality of care provided in nursing facilities in other states, the District of Columbia is implementing an initiative to improve care provided in its nursing facilities. These initiatives are guided by recommendations from the Institute of Medicine's (IoM) report entitled, *Improving the Quality of Long-Term Care.*[19] Plans include increasing survey efforts, particularly for poor performers, and increasing penalties for non-compliance. The District also anticipates that the Aging and Disability Resource Center[20] will house information for consumers on the quality of nursing facility providers. The plans for case-mix reimbursement mentioned previously will also sharpen the quality of care provided. The District also plans to develop training, education and competency standards, and to increase the amount of training given to providers.

E. Emerging Issues Affecting Nursing Facility Services

1.Staff Shortages

The residential LTC industry is suffering from a shortage of skilled nursing staff. This shortage is felt at all levels of training, from the certified nursing aides (CNAs) who feed and bathe patients and perform other custodial care, to the registered nurses (RNs) who provide medical care.

2.Medicaid Waivers

The District of Columbia has received waivers that provide more residential options funded by Medicaid for the elderly in the MR/DD populations. In 1998, the District implemented Medicaid waivers for the elderly in the MR/DD populations. The waivers do not currently pay for residential long-term care services, as alternatives to nursing facilities.

The "Assisted Living Regulatory Act of 2000" was signed by the Mayor in March of 2000 and became D.C. Law 13-127 in June of 2000.[21] The regulations set minimum standards for

[19] Gooloo S. Wunderlich and Peter O. Kohler, *Editors*; Committee on Improving Quality in Long-Term Care, Division of Health Care Services. Available at http://www.nap.edu/catalog/9611.html

[20] In addition to the quality measures, the planned Resource Center will also help direct DC residents to Medicaid nursing facilities in the District of Columbia instead of neighboring Maryland and Virginia.

[21] Details of the regulations can be found in DC Code D. VIII, T. 44, Subt. I, Ch. 1.

community residential facilities previously covered under Chapter 34 of Title 22 of the DC Municipal Regulations and any other facilities that assist individuals with ADLs.

3.Long Term Care Resource Center

The Office on Disability and Aging/Medical Administration Assistance is currently planning to implement an Aging and Disability Resource Center of long-term care information for the aged and physically disabled. The Resource Center will provide information to all individuals or family members and friends of individuals in need of long-term care. The Center plans to also serve as a single point of entry for persons needing Medicaid long term care services. It will help consumers choose among the alternatives. It will also assist in the expediting the Medicaid eligibility process.

If the redesign of these service systems is successful, the District of Columbia will examine the inclusion of other populations, such as individuals with mental illness and children with special health care needs.

1.Staff Shortages

The residential LTC industry is suffering from a shortage of skilled nursing staff. This shortage is felt at all levels of training, from the certified nursing aides (CNAs) who feed and bathe patients and perform other custodial care, to the registered nurses (RNs) who provide medical care.

2.Medicaid Waivers

The District of Columbia has received waivers that provide more residential options funded by Medicaid for the elderly in the MR/DD populations. In 1998, the District implemented Medicaid waivers for the elderly in the MR/DD populations. The waivers do not currently pay for residential long-term care services, as alternatives to nursing facilities.

The "Assisted Living Regulatory Act of 2000" was signed by the Mayor in March of 2000 and became D.C. Law 13-127 in June of 2000.[22] The regulations set minimum standards for community residential facilities previously covered under Chapter 34 of Title 22 of the DC Municipal Regulations and any other facilities that assist individuals with ADLs.

3.Long Term Care Resource Center

The Office on Disability and Aging/Medical Administration Assistance is currently planning to implement an Aging and Disability Resource Center of long-term care information for the aged and physically disabled. The Resource Center will provide information to all individuals or

[22] Details of the regulations can be found in DC Code D. VIII, T. 44, Subt. I, Ch. 1.

family members and friends of individuals in need of long-term care. The Center plans to also serve as a single point of entry for persons needing Medicaid long term care services. It will help consumers choose among the alternatives. It will also assist in the expediting the Medicaid eligibility process.

If the redesign of these service systems is successful, the District of Columbia will examine the inclusion of other populations, such as individuals with mental illness and children with special health care needs.

III. SUMMARY RESOURCE INVENTORY AND HISTORICAL UTILIZATION OF SERVICES

A. Resource Inventory

The District of Columbia has 21 non-federal nursing facilities, five of which are hospital-based and 16 of which are freestanding facilities. In addition, there are two federal facilities that provide nursing care, the Veterans' Administration (VA) Nursing Home and the U.S. Soldiers and Airmen Home. The majority of homes are run on a non-profit basis. **Table 5** provides a listing of all of the District of Columbia's nursing facilities, whether they are hospital-based or freestanding, number of beds, residents and occupancy rates.

Table 5. Nursing Facilities in the District of Columbia, 2001

Facility Name	Freestanding vs. Hospital	Ownership Status	No. Beds	No. Residents	Occupancy Rate	Census Date
Capitol View Subacute Howard University Hospital	H	N	28	24	85.7%	11/16/00
Carroll Manor Nursing & Rehab Center	H	N	240	228	95.0%	08/09/00
Grant Park Care Center	F	P	296	282	95.3%	03/15/01
Greater Southeast Community Center for the Aging	F	N	183	169	92.3%	02/15/01
Hadley Memorial Hospital SNU	H	P	103	85	82.5%	02/02/01
Ingelside	F	N	66	60	90.9%	01/10/01
J.B. Johnson Nursing Center	F	G	244	198	81.1%	01/11/01
Jeanne Jugan Residence	F	N	20	20	100.0%	04/19/01
Knollwood	F	N	50	49	98.0%	04/11/01
Lisner Louise Home	F	N	60	60	100.0%	10/27/00
Medlink Nursing Center	H	N	152	111	73.0%	06/23/00
Medstar Manor at Lamond Riggs	F	N	68	67	98.5%	11/08/00
Methodist Home of DC	F	N	25	19	76.0%	12/27/00
Northwest Health Care Center	F	P	355	332	93.5%	05/26/00
Rock Creek Manor	F	P	180	172	95.6%	01/26/01
Sibley Memorial Hospital Renaissance SNU	H	N	18	15	83.3%	11/02/00
Stoddard Baptist Nursing Home	F	P	164	164	100.0%	02/23/01
Thomas House	F	N	53	52	98.1%	08/16/00
Washington Center for Aging	F	G	263	254	96.6%	09/21/00
Washington Home	F	N	189	173	91.5%	12/18/00

Washington Nursing Facility	F	P	340	315	92.6%	04/13/00
All District Homes	-	-	3,097	2,849	92.0%	-

Notes: H=Hospital-Based; F=Freestanding; N=Not-for-Profit; P=For-Profit; G=Government (DC)

Source: CMS, Nursing Home Compare (http://www.medicare.gov/nhcompare/home.asp)

B. Historical Utilization Trends

Due to the potential for substitution between different settings, the current District system for nursing facilities, ICF/MRs and community-based residential facilities (CRFs) is outlined to the extent data were available. For each type of service, capacity, use, reimbursement and quality efforts are reviewed.

The following table provides summary information available regarding the capacity and utilization of nursing facilities and residential alternatives available in the District of Columbia. There are considerably fewer residential alternatives relative to nursing facility beds.

Table 6. Residential Facilities' Capacity and Utilization, 2000-2001

Service	Facilities	Beds	Users	Occupancy
Nursing Facility[a]	21	3,097	2,849	92%
ICF-MR	129	851	874[b]	N/A
Community Residential Facility				
Mental Illness and Aged	200	1,875	N/A	N/A
MR/DD	33	174	153	88%

[a] Excludes federal facilities.
[b] Medicaid financed users throughout 2000.
[c] Identified based on the Yellow Pages.
Sources: Nursing facility data based on the Center for Medicare and Medicaid Services Nursing Home Compare Database accessed 8/01. ICF/MR data based on HCFA-64 and -2082 reports, DC Office on Disabilities and Aging. Community Residential Facility data based on DC Health Regulation Administration and the number of MR/DD users based on a Personal communication with MRDDA, August 17, 2001.

Disregarding the federal facilities, the District of Columbia has a total of 3,097 nursing beds.[23] This corresponds to 47.3 beds per 1,000 elderly (age 65+) residents or 383.1 beds per 1,000 very old (age 85+) residents.[24] These ratios are slightly smaller than their national counterparts; nationally, there are 52.5 beds per 1,000 elderly and 445.6 beds for every 1,000 of the very old.[25]

At the time of CMS's last survey of nursing homes (late 2000 to early 2001), there were 2,849 residents in the District of Columbia. Occupancy rates in the District of Columbia range from 73 to 100 percent, with an average of 92 percent. This is considerably higher than the national occupancy rate of 83 percent in 1999.[26]

[23] Data from Nursing Home Compare available at www.medicare.gov/nhcompare/home.asp

[24] Information from Census 2000 and Nursing Home Compare.

[25] Harrington, et.al. (1999).

[26] American Association for Retired Persons Public Policy Institute (2000). *Across the States 2000: Profiles of LTC Systems*. Washington, D.C.: AARP Public Policy Institute.

III. PROJECTIONS

The projections presented here include Nursing Facility beds used for rehabilitation. The calculation is based on the total year 2000 population and the percentage of users.

A. Methodology

The standard unit of demand in this methodology is the person-year of service. Due to a lack of District-specific utilization data by socio-demographic characteristics, national nursing facility use rates were used.

Population: The following five subgroups of the District of Columbia population were tracked over a six-year period:

(1) Children age 0 to 17
(2) Adults age 18 to 64
(3) Elderly age 64 to 75, by race (African-American vs. Other) and by sex
(4) Elderly age 75 to 84, by race (African-American vs. Other) and by sex
(5) Elderly age 85 and older, by race (African-American vs. Other) and by sex

The elderly are tracked by race and sex because institutionalization rates differ significantly by these criteria and because the population distribution of the District of Columbia is substantially different from that of the nation at large. Actual results from the 2000 Census[27] were combined with state-level population projections[28] to project the population distribution of the District of Columbia forward to 2007 by each of the above subpopulations. The total projected District population was then adjusted to be consistent with that used in other Chapters of this document.

Base Utilization: The national rates of nursing home use by age, sex, and race from two sources are presented in **Table 7**:

(1) William Spector, et.al.'s (2000) analysis of the 1996 Medical Expenditure Panel Survey (MEPS) Nursing Home Component provides the adult (age 18 to 64) institutionalization rates.[29]

[27] http://www.census.gov/Press-Release/www/2001/tables/redist_dc.html.

[28] http://www.census.gov/population/www/projections/stproj.html.

[29] Spector, W., J. Fleishman, L. Pezzin, et.al. (2000).

(2) A Lewin Group analysis of the 1998 Medicare Current Beneficiary Survey (MCBS) provides the rates for elderly individuals (age 65 +) using nursing facilities, by age group, sex, and race. This data source is used because the rich demographic information and relatively large sample size allows breakouts of the elderly population into smaller subgroups. The fact that the survey is limited to Medicare beneficiaries is of only modest concern as more than 95 percent of the elderly are enrolled in Medicare.

Table 7. Rate of Nursing Home Use (in Person-Years) per 1,000 Members of the Subpopulation, by Age Group, Sex, and Race

		African-American		Other	
Age Group	Source	Male	Female	Male	Female
0 to 17	Glick	1	1	1	1
18 to 64	Spector	1	1	1	1
65 to 74	MCBS	33	21	14	14
75 to 84	MCBS	55	84	43	64
85 and older	MCBS	264	260	145	281

B. Calculations

Calculating Demand for Nursing Home Beds: Age/sex/race-specific NF utilization rates were used to calculate the number of individuals from each subgroup who would demand nursing facility services at national use rates (**Table 8**). It is apparent that projections based on national use rates overstated the propensity to use NF services in the District of Columbia. One possible explanation for this discrepancy could be District residents' use of facilities outside the District of Columbia. The estimate by the ratio of actual NF use in 2001 was normalized (from CMS' Nursing Home Compare database[30]) to the observed NF use for 2001. This normalized demand is presented in **Table 9**.

Table 8. Estimated Nursing Facility Residents Based on National Use Rates

Age	Race	Sex	Inst.Rate	Total Pop.	Inst.Pop.
0 – 17			0.001	121,761	122
18 – 64			0.001	404,911	352
65 – 74	Black	Male	0.033	8,578	286
		Female	0.021	13,011	277
	White	Male	0.014	5,717	78
		Female	0.014	6,093	88
75-84	Black	Male	0.055	5,473	301
		Female	0.084	10,159	858
	White	Male	0.043	3,320	144

[30] Nursing Home Compare is available online at http://www.medicare.gov/nhcompare/home.asp

		Female	0.064	4,531	288
85+	Black	Male	0.264	1,584	418
		Female	0.260	4,572	1,187
	White	Male	0.145	1,042	151
		Female	0.281	2,308	649
Total				593,059	5,200

Table 9. Nursing Facility Bed Need Calculation

Methodology Steps	Factor	Calculation
Predicted DC NF Residents based on National Use		5,200
Normalized to 2001 DC use	0.549	2,854
Bed Need at 95 percent occupancy		3,004
Licensed Beds		3,093
Current Beds in Excess of Need Estimate - 2007		89

.

Demand for nursing facility beds in the District of Columbia is projected to change very little over the next six years. The number of beds demanded falls slightly between 2001 and 2004 and then rises again slightly.

If the occupancy rate remains below 95 percent, and there is no reduction in supply, no need for new nursing facility beds is predicted (as demonstrated in Table 9, where an access of 89 beds is shown).

Further supporting this conclusion is the presence of the District of Columbia's new Medicaid HCBS Waiver program. While it currently serves only a small number of disabled and elderly persons, plans to expand the program are underway. This will allow a number of elderly and disabled persons who would otherwise use institutional services to receive care in the community, lowering demand for nursing facility beds.

The finding that there is no apparent need for additional beds in the next five years should be treated with caution when considering applications for expansion of supply in specialized nursing facility services.

V. CRITERIA AND STANDARDS

A. Availability

Availability is defined as the need projection indicating the supply of resources in relation to the need or the demand for resources. The availability standards for nursing facility services rendered in the District of Columbia are as follows:

(1) The number of nursing facility beds in the District of Columbia should be sufficient to meet the needs of District residents. New facilities and facilities requesting expansion should demonstrate that the proposed services are consistent with the specific needs of District residents requiring such services.
(2) Sufficient beds should be available for each level of care and for all age/risk categories.
(3) New facilities and existing facilities requesting expansion should demonstrate and/or specify the age-risk category for which they are applying.

B. The need for the beds should be requested in an age specific category and level of care.

(1) Evidence that the current system-wide complement of nursing facility beds has maintained an average occupancy rate of 95 percent based on licensed bed capacity for a continuous period of at least six (6) months unless existing facilities are unable to meet needs of target population.

C. Accessibility

Accessibility is the measure of the ease of entry of services for the consumer.

In order to assure access to nursing facility beds for District residents, the following accessibility standards should be satisfied:

(1) Services should not be denied because of age, sex, race, creed, religion, or organizational affiliation in the District of Columbia. The facility should be able to document the reason why an individual was denied admission.
(2) Nursing facilities should provide all potential referral agencies with information concerning the scope of their services and limitations. Environmental conditions, placement procedures, admission criteria and financial requirements should be included in this information.
(3) All facilities must comply with local laws and regulations concerning accessibility for nursing facilities.

D. Continuity

Continuity is the structure, coordination and delivery of services on a continuous basis and in a timely manner.

Health and personal care services necessary to maintain a nursing facility patient in optimal health should be available to the residents. The continuity standards for nursing facilities are as follows:

(1) Nursing facilities should have established mechanisms to ensure continuity of care and coordination of services with hospitals land other service providers in order to provide full array of services necessary to meet a resident's acute, long term, and other health needs.
(2) Facilities should have a coordinated program that ensures that each patient has a planned program of continuing care, irrespective of primary financing source.
(3) Facilities should be able to demonstrate staffing patterns consistent with the Department of Health standards that ensure continuity of care for all patients at optimal levels.
(4) Facilities should require that all referrals include, at a minimum, written summaries of care rendered as well as current patient care data. The nursing facility should provide the same information for referrals to other agencies requiring health status information.

E. Quality

Quality is defined as the degree of excellence characterized by levels of technical competence, appropriateness, safety and beneficial impact.

The standards of quality for nursing facility services are as follows:

(1) Nursing facilities should provide a range of services that is consistent with their certification and the needs of the patient.
(2) Each nursing facility resident should have a care plan that is reviewed and revised on a regular basis by all providers of care.
(3) Each nursing facility resident should receive a comprehensive care assessment on a periodic basis to determine: the appropriateness of their level of care, their need for additional services that can be provided by the facility, and their habilitation to a service level other than the nursing facility.
(4) A medical director must oversee and coordinate the provision of medical care in the nursing facility.
(5) Nursing facilities should demonstrate the existence of a quality assurance system that complies with District and federal regulations at a minimum.
(6) Nursing facilities should have a written policy providing for physician supervision of patients and the prescription of a planned regimen for total patient care.
(7) Each facility must comply with all licensure and staffing requirements of District and federal regulations.
(8) Nursing facilities should demonstrate programs and/or provisions for staff development including state of the art services and psychosocial services.
(9) All personnel employed by the nursing facility, both professional and nonprofessional, should be qualified/certified to render the services provided.
(10) Nursing facilities should have policies and procedures for periodic evaluation of their employees' skills and performance.

(11) The facility should have a current description of its utilization review plan that is conducted by appropriate staff. The utilization review should identify medical care evaluation studies and appropriateness of placement.
(12) Nursing facilities should demonstrate programs and/or efforts to assure community participation.
(13) Develop a written policy regarding Advance Directives to include Do Not Resuscitate (DNR) status.

In the District of Columbia, the Department of Health has developed new nursing facility regulations required to implement D.C. Law 5-48. These regulations are based upon the recommendations of the Task Force on Nursing Facility Licensure.

F. Acceptability

Acceptability is defined as the degree of satisfaction of the services to the community and its users.

The standards of acceptability for nursing facility services are as follows:

(1) Each nursing facility should have a Patient's Bill of Rights and should communicate these rights to the resident and/or their family.
(2) Nursing facilities should have an established, written consumer grievance procedure.
(3) Nursing facilities should demonstrate efforts to encourage community participation.
(4) Nursing facilities should establish procedures for the periodic assessment of their service acceptability as viewed by consumers, community, the nursing facility industry and other health providers (referral sources).
(5) The nursing facility should assure that service delivery mechanisms do not violate a patient's privacy or dignity, or compromise confidentiality.
(6) All nursing home residents or their designees should have the option to participate in care planning, review and evaluation of services.
(7) All facilities must comply with District and federal regulations concerning safety and other environmental factors.
(8) Nursing facilities should attempt to satisfy the cultural needs of their resident population.

The District of Columbia Ombudsman program enhances the acceptability of nursing facility care for District residents and serves to ensure that the patients' point of view is considered in the planning, development, and regulation of long term care services.

G. Cost

Cost is defined as the total expenses and economic consequence of the provision of services, including provider cost, consumer cost, opportunity costs and societal costs.

(1) Any changes to an existing nursing facility or proposal for a new nursing facility should not exceed the average cost to the consumer beyond the local market place.

H. The payer source must be defined in the applications, i.e. Medicaid, Medicare, private payer or other.

I. The applicant shall be financially capable of ensuring that all services, beds and the facility shall be compliant with safety and/or licensure standards.

VI. GOALS AND OBJECTIVES

Goal 1: Provide all District residents with the option to obtain custodial care in the setting of their choice.

Objectives:

1.1. Develop additional community-based residential facilities, including assisted living.

1.2 Expand the residential options for long-term care supported by Medicaid

1.3. Provide District residents with information to make informed decisions.

1.4. Establish a Long Term Care Resource Center.

Goal 2: Enhance the quality of care provided in the District of Columbia's nursing facilities.

Objectives:

2.1. Implement outcomes-based measures of care, specific to long term care services.

2.2. Research the Minimum Data Set (MDS) findings from facility to track LTC outcomes over time by facility.

2.3 Explore the use of person-centered measures of care through direct a series of timely surveys of residents.

2.4 Develop a tool to ensure that facilities comply with quality standards set by accrediting or regulatory bodies.

2.5 Promote additional training of all health care delivery professionals working within nursing facilities, including nurses aides, on the topic of implementing short turn around quality improvement methods.

Goal 3: Improve the quality of data for planning for nursing facilities.

Objectives:

3.1 Develop a comprehensive residential facility data system in the District of Columbia.

3.2. For nursing facilities, capitalize on existing data collected for CMS' Online Certification and Research (OSCAR) data base and the Minimum Data Set (MDS) to develop a more timely and complete view of nursing facilities in the District of Columbia.

3.3 For other types of residential care, develop a standardized reporting mechanism in terms of information requested and timeframe. At a minimum, include beds and residents by age.

HOME HEALTH

I. INTRODUCTION

Home health care, includes the in-home provision of health services including nursing care, social work, occupational therapy, physical therapy, speech therapy, home health aide support, and staff-assisted hemodialysis services. When provided in addition to one of these services, personal care services may also be considered home health care.

Supportive home care of a non-medical nature--such as Meals-on-Wheels, and homemaker and companion services are supplemental services; however they are not considered home health care.

A home health agency (HHA) is defined as an agency, organization that provides a program of health care to sick or disabled individuals living at home. In addition to care provided at an individual's home, home health services may also be provided to individuals residing in a community residential facility; however, District of Columbia Municipal Regulations (DCMR 22, Chapter 34) preclude HHAs from providing services to an individual in a community residential facility for more than 72 hours.

The vast majority of HHAs are either freestanding or hospital-based, and the care provided can either be directly by the agency or through contractual arrangements.

II. BACKGROUND AND TRENDS

A. National and District of Columbia Trends

1. Use

Nationally, in 1998, beneficiaries averaged 36.4 visits per patient. Total Medicare home health spending equaled $20.6 million in 1998, a decrease of almost $7 million from 1997. This is in stark contrast to the overall United States spending under Medicaid's Personal Care program, which is over one and a half times greater than spending under Medicaid's Home Health program, $3.5 billion compared to $2.3 billion.

In the District, under Medicaid, personal care is the most used home care service with 6,641 District residents receiving services, more than double the 2,914 individuals receiving Medicaid Home Health services. However, in FY 2000 spending under Medicaid's Home Health program was almost 7 times greater than spending under the Personal Care program, $12.4 million compared to $1.8 million. In addition, among the 50 states and the District of Columbia, the District had the second lowest Medicaid home health spending as a percent of total Medicaid spending in 1999.

Home health care services in the District of Columbia are in some instances financed through managed care organizations (MCOs). Managed care is more prevalent in the employer-based health insurance market. Medicaid managed care is also available to District Medicaid beneficiaries. More managed care companies are opting out of the Medicare+Choice market. These companies typically focus on various cost-saving mechanisms and utilization review to control costs. As a result of managed care, hospital stays are shortened and patients are discharged to home care services for continued rehabilitative care. Thus, the demand for home health care services is increasing.

Data from the 1996 State Health Planning Development Agency (SHPDA) survey revealed that in 1994, 37 percent of the District of Columbia residents receiving home health services lived in Northwest, 6 percent lived in Southwest, 32 percent lived in Northeast, and 25 percent lived in Southeast.

2. Reimbursement

Medicare and Medicaid are key sources of financing for home health services. The home health benefit under Medicare was designed to provide less expensive "follow-up care" after acute inpatient care. The original intent of Medicaid and Medicare was to:

(1) Provide lower level acute care services, such as intermittent skilled nursing care and physical therapy services, in the home in order to reduce inpatient length of stay; and
(2) Prevent readmission of patients with post-hospitalization acute exacerbation.

Medicare reimbursement for home health services is based on:

- A prospective payment system (PPS).
- A fixed amount for each patient for each 60-day episode of care.
- An adjustment for the severity of the patient's condition, as well as geographical differences in wages.

Medicaid covers home health services mainly under three separate programs:

(1) Medicaid Home Health, basically providing services to individuals entitled to skilled nursing facility services
(2) Personal Care program, mainly intended to provide services that assist with basic activities of daily living, including eating, bathing, and dressing.

(3) Home and Community Based Waiver program, providing some flexibility in the delivery of home care services, aimed at providing an alternative to institutionalization.

Medicaid reimbursement for home health services is based on a flat rate fee schedule. In 1998, the average Medicaid reimbursement rate for a RN home health visit in the District of Columbia was $65 per visit. The average Medicaid reimbursement rate for a home health aide visit was $12.50 per hour.

i. Quality

In 1983, the Council of the District of Columbia enacted the Health Care and Community Residence Facility, Hospice and Home Care Licensure Act of 1983 to empower the Department of Consumer and Regulatory Affairs to license and regulate home health services.

One means of measuring the standards of practice in the District of Columbia is through the requirement that agencies must secure Medicaid and Medicare certification. In addition, the collection of Outcome and Assessment Information Set (OASIS) data, which will be used to measure outcomes for home health patients receiving skilled services, will provide the District of Columbia with a means of monitoring quality.

B. Issues Affecting Home Health Services in the District of Columbia

1. Medicaid Home and Community-based Waiver

Home and community-based services waivers allow states to provide home and community services not usually covered by Medicaid to individuals who would otherwise require institutionalization. In 1998, the District of Columbia's Office of Health Care Financing submitted an application and gained approval for a home and community-based services waiver in an effort to decrease institutional expenditures and increase access to home and community-based services. The waiver enables the District of Columbia to provide services to elderly individuals with incomes below the federal poverty guideline and a nursing home level of disability.

When the waiver was approved, it was anticipated that services would be provided to approximately 75 individuals the first year and would grow to 225 individuals the third year. The District of Columbia is addressing some of these concerns in a waiver amendment. Once approved, the waiver will provide services to adults with disabilities under age 65 and will also allow for the provision of consumer-directed attendant care.

In addition to the elderly waiver, the District of Columbia also operates a waiver program for adults with mental retardation and developmental disabilities. The majority of services

covered under this waiver are considered home care rather than home health. These services include, but are not limited to, homemaker and chore aide services, personal care, transportation, and respite care.

Up to 225 individuals can be served under the MR/DD waiver, as of August 2001, 123 consumers were served. The waiver has been amended to include services to individuals between the ages of 14 and 22 with MR/DD.

2. Growth In "High Tech" Home Health

Historically, home health care revolved around skilled nursing and personal care services. However, in recent years there has been significant growth in the "high tech" home health market. "High tech" home health care has become the all-inclusive term used to describe a variety of treatments including: parenteral nutrition, intravenous (IV) antibiotic therapy, hydration, home chemotherapy, IV pain management, and ventilator and tracheostomy services to dependent patients. These treatments serve a broad range of populations, one of the most notable being infants and children with special needs.

As state-of-the-art technology in pediatric care has increased dramatically in recent years, so has the number of infants and children with special needs. A decade ago, many of these children with chronic illnesses and handicapping conditions would have died or required institutionalization. Now, many survive in the comfort of their own home due to the advancement in home health care services available.

C. Olmstead Decision

The Supreme Court issued the Olmstead decision in July 1999 said it was a violation of the Americans with Disabilities Act to institutionalize individuals with disabilities unnecessarily. Thus, enabling individuals with disabilities the opportunity to live in the most integrated setting appropriate to their needs. As a result of the decision, states have the obligation to seek community-based services for disabled residents and are reassessing institutionalized individuals with disabilities to determine if care is being provided in the most appropriate setting. Many individuals will be moved from institutions to home and community-based settings.

D. Medicare Prospective Payment System

The Balanced Budget Act (BBA) implemented prospective payment for Medicare home health services in October of 1998. Prior to that Home Health Agencies were reimbursed on a cost-based system.

Table 1 demonstrates that in the District of Columbia, the number of Medicare home health patients, visits, and payments all dropped from 1997 to 1998. In addition, the BBA implemented other changes including: (1) transferring home health payments not associated with a three day hospitalization to Medicare Part B; (2) basing payment on the

cost of the location where services are delivered rather than on the costs of the location of the business office; and (3) eliminating venipuncture as a service that may qualify beneficiaries for other home care services.

The number of Medicare-certified home health agencies decreased 28 percent between 1997 and 1999, following the implementation of the BBA - falling from 10,807 to 7,747. In addition, the number of home health patients, the number of home health visits, and the expenditures per patient all decreased, as shown in **Table 13.**

Table 1. Medicare Home Health Benefit Payment Data, 1997-1998
Patients, Visits, and Payments in the District of Columbia

	1997	1998
Total Patients	8,001	7,073
Total Visits	349,731	257,318
Total Payments	$ 27,327,142	$ 20,569,510
Visits per Patient	44	36
Payments per Patient	$ 3,415	$ 2,908
Payments per Visit	$ 78	$ 80

Source: Health Management Resources, Inc., 2001

E. Outcome Assessment Information Set (OASIS) Implementation

Data items captured by OASIS include socio-economic, environmental, support system, and health status, as well as functional status attributes of adult patients and selected attributes of health service utilization. Despite being created with the goal of measuring patient outcomes, the set of data items provided by OASIS can also be used in clinical assessments, care planning, agency-level case mix reports, and internal HHA performance improvement.

OASIS will be useful in measuring patient outcomes, as well as in assessing patient condition and care planning.

1. Personal Assistance Services and Supports (PASS) Grant

Personal care is one of the most frequently used home care services. The Medical Assistance Administration (MAA) is the largest funding source of personal care services in the District of Columbia, funding Personal Care Aide Services and Home Health Aide Services under Medicaid and serving approximately 1,700 persons annually. To be eligible under the Home Health program, individuals must require skilled nursing services.

Personal assistance services provided through the elderly and MR/DD waivers, as well as services provided through Adult Protective Services and the Office on Aging, supplement Medicaid's Home Health and Personal Care programs. The total number of individuals served under these programs is just over 1,000. The various programs have different eligibility requirements, provide different services, and use different methods of access.

In order to build the infrastructure for a cost-effective personal assistance service that allows for consumer direction, the District of Columbia has submitted a proposal to CMS to fund the Personal Assistance Services and Supports (PASS) project. This will allow for

the coordination of the various programs providing personal care services in order to provide individuals the most appropriate care available.

The goals of the project include: setting appropriate rates for personal assistance services by working directly with consumers and providers; creating an information system to track budgets and expenses; providing a variety of services, including provider agency training, a Job Bank, consumer training, training for personal assistants, urgent response system, and a consumer mentor program to work with clients and to assist in conflict resolution.

2. Resource Center

The Resource Center is based on similar efforts in Wisconsin and New Jersey. It will serve the aged and individuals under 65 with physical disabilities beginning in fiscal year 2002 and will eventually phase-in individuals under 65 with MR/DD. The main purpose of the Resource Center is to create a single point of entry to access the long-term care system.

Major long-term care pathways, including institutions, home care agencies, and hospitals, will be required to refer people in need of long-term care services to the Resource Center. The Resource Center will provide information to individuals and will help determine eligibility for and coordinate Medicaid and other public programs. In addition, the information provided will enable individuals to make an informed decision as to which type of long-term care services they would like to receive and the setting in which they will receive them.

III. SUMMARY RESOURCE INVENTORY AND HISTORICAL UTILIZATION TRENDS FOR HOME HEALTH

As of August 2001, there were twenty Medicare-certified home health agencies operating in the District of Columbia. The types of caregivers most frequently employed by respondents to a SHPDA survey were Registered Nurses, Personal Care Aides (Home Health Aides), Social Workers, Speech Pathologists/Audiologists, Licensed Practical Nurses, and Physical Therapists, Psychologists, Counselors, Respiratory Therapists and pharmacists are the least frequently employed caregivers.

IV. NEED METHODOLOGY

The following method was used to calculate the demand for home health services: First, age/sex/race-specific home health utilization rates (number of home visits per patient) were used to calculate the number of individuals who would demand home care services at local use rates to demonstrate a current trend. Second, socio-demographic data from the District as well as other factors contributing to the need for home health services, such as various debilitating ailments and post-surgical conditions were used to determine

the projected demand for home health services. Finally an estimate of the increase in the ratio of actual home health care use in 2001 compared to the observed home health use for 1998 was also calculated.

V. CRITERIA AND STANDARDS

A. Availability

Availability is defined as the need projection indicating the supply of resources in relation to the need or the demand for resources.

(1) The number of home health agencies should be sufficient to provide services that meet the needs of all levels of care and all risk and age categories.

(2) There should be a sufficient number of licensed and credentialed staff to deliver care to all age and risk categories.

B. Accessibility

Accessibility is the measure of the ease of entry of services for the consumer.

Home health services should be accessible to all persons for whom they are appropriate, regardless of age, sex, sexual orientation, race, color, creed, national origin, disability, prior hospitalization, diagnosis, prognosis. The accessibility standards for home health services are as follows:

(1) There should be high quality home health agencies that do not limit the provision of services to residents without regard type of imbursement.
(2) Written policies should govern provision of care to medically indigent persons at a reduced charge and/or without charge and should be consistent with the District's Health Plan. Clients should be made aware of these policies during intake.
(3) Special payment plans should be developed providing for scheduled payments and graduated fees for individuals unable to make lump sum payment for services rendered and those unable to pay full charges on an ongoing basis. Clients should be made aware of these special payment plans during intake.
(4) To improve access, certification in Medicaid and Medicare is beneficial.
(5) Home health agencies should have written policies to govern admission and discharge of patients.
(6) Home health agencies must have a 24-hour plan of care for each patient.
(7) Home health agencies should have available information about charitable and other human service organizations as possible sources of financial assistance and refer patients, as appropriate, to such resources.

(8) Home health agencies should take actions to ensure that the public is aware of the services they offer.
(9) Home health agencies should have the capacity to assess patient service needs within a 48-hour period of contact, or less if indicated by the patient's clinical condition.

C. Continuity

Continuity is the structure, coordination and delivery of services on a continuous basis and in a timely manner. Continuity of care includes:

Home health services should be coordinated within the health care system to provide appropriate and timely services to clients. Continuity standards for home health services are as follows:

(1) Home health agencies should establish mechanisms to ensure continuity of care and coordination of services with hospitals and other providers of health care and in-home services to ensure provision of a full range of services. The responsibility for case management should be clearly designated for each recipient even when the case is managed by an entity other than the home health agency.
(2) Referrals to and from home health services, including readmission, should include patient care data to ensure that continuity of care is maintained.
(3) Home health services should have written guidelines for referral of patients for different or additional services, including procedures for carrying out referrals.

D. Quality

Quality is defined as the degree of excellence characterized by levels of technical competence, appropriateness, safety and beneficial impact. The standards of quality for home health services are as follows:

(1) Home health agencies should provide a range of home health services consistent with the needs of their particular clients.
(2) Home health services will provide, at a minimum, a quality assurance program. Professional and paraprofessional personnel employed by or acting on the behalf of home health agencies for the purpose of patient care should be qualified to render home health care.
(3) Professional personnel shall be licensed by the appropriate health occupations board (Refer to Health Occupations Revision Act of 1985, DC Law 6-99)
(4) Screening mechanisms shall be in place to determine the competency of paraprofessional personnel.

(5) All providers should have written policies requiring an overall evaluation of the agency's total program at least once a year.
(6) Agencies should assure that there is a Patient Bill of Rights written for and explained to each patient under their care.
(7) All agencies should have an Advance Directives policy to include Do Not Resuscitate (DNR) status.

E. Acceptability

Acceptability is defined as the degree of satisfaction of the services to the community and its users. The standards of acceptability for home health services are as follows:

(1) Each provider should have an adopted Bill of Patient Rights, and should make these rights known to clients as part of an informed consent policy and procedure.
(2) Each provider should actively seek community participation, through the use of policy- making boards, on the home health services they provide, and be able to demonstrate how this in-formation will be used to ensure patient satisfaction.
(3) Each provider should have written, publicized grievance procedures for clients as well as staff that permit expression of concerns without fear of reprisal.
(4) Services should be provided in a manner that is respectful and accepting of the patient's personal health behavior, even when that behavior has contributed to the condition for which the patient is being treated.
(5) Services should be delivered in a manner that maintains the patient's privacy, confidentiality, and dignity.
(6) The selection of treatment and the availability of support services should be conducive to patient cooperation and participation.
(7) Service should be provided in the cultural and linguistic context most appropriate to the patient.

F. Cost

Cost is defined as the total expenses and economic consequence of the provision of services, including provider cost, consumer cost, opportunity costs and societal costs.

Home health care should be provided to all District residents in need of services at a reasonable cost. The standards governing cost of home health services are as follows:

(1) Providers should utilize and routinely adhere to generally acceptable accounting principles, which assures effective and efficient fiscal management and operation.
(2) Financial feasibility with audited financial statements illustrating at least six months operating expenses shall be demonstrated.
(3) An annual audit shall be submitted.

(4) Funding sources shall be identified and documentation provided to demonstrate that the business will be financially viable for at least three years from the initial operation date.

V. GOALS and OBJECTIVES

Goal 1: Provide services to all residents of the District of Columbia in need of home health care regardless of location

Objectives:

1.1: Determine the need to expand District waivers and broaden eligibility requirements.

1.2 Investigate the feasibility of serving new population groups.

1.3 Set up consistent, regular communication among District offices responsible for various aspects of the long term care system, in order to support the expansion of home health and related home and community based services in the District of Columbia.

1.4. Improve understanding of the home health and Home and Community-Based Services currently being used in the District of Columbia.

1.5 Collect basic home health utilization information for users of all types of home care services, from all payers.

Goal 2: Improve the quality of home health services

Objectives:

2.1 To investigate the development of tangible methods of monitoring the quality of home health services.

2.2 Analyze data as available from The Outcome and Assessment Information Set (OASIS) with respect to utilization and quality, and outcomes.

2.3 Investigate the development of a set of quality indicators.

2.4 Promote additional training of all health care delivery professionals on methods of improved home health care delivery, i.e. best practices.

ADULT DAY SERVICES

I. INTRODUCTION

Adult Day Care Services are defined as:

> A community based group program designed to meet the needs of functionally impaired adults through an individual plan of care. A structured comprehensive program provides a variety of health, social and related support services in a protective setting during any part of a day but less than 24-hour care.

Adult Day Care (ADC) settings provide services to diverse populations, including frail older persons, physically disabled adults, substance abusers, people with mental illness, people with mental retardation, and individuals with developmental disability.

There are two basic models for ADC programs: medical and social. Medical day care focuses on clinical services to maintain or restore mental and physical functional ability, while social ADCs usually include a strong social component in addition to a health component. However, the needs of the population being served define the focus or specialty of each program, regardless of whether it is community or hospital based one. For example, hospital based programs, given the resources of a larger medical institution, may target their services to physically disabled patients requiring intensive therapeutic and rehabilitative services that focus on restoration of functional capacity.

In contrast, community based programs for older persons may focus more on health maintenance and the prevention or delay of further deterioration than their hospital-based counterparts. Facilities that do not provide medical services, such as physical therapy services but do provide other forms of therapy that enhance the patient's cognitive abilities - recreational therapy, exercise - are considered to be the social adult day care model.

Since most programs serve populations with multiple needs, the optimal program meets both medical and social needs. The medical model and combination medical/social model day care programs are those programs identified as medically supervised day care programs or medical day care programs.

The National Institute on Adult Daycare (NIAD) divides the level of need for adult day services into three categories:

(1) Level of Need 1 – The participants at Level of Need 1 is in need of socialization, some supervision, service, and minimal assistance with Activities of Daily Living (ADLs).
(2) Level of Need 2 – The individual at Level 2 is in need of moderate assistance, moderate meaning roughly 30 to 60 percent of the time. Needs may include health assessment, oversight or monitoring by a nurse, therapy services at a maintenance level and moderate assistance with 1-3 ADLs.

(3) Level of Need 3 – The participant at Level of Need 3 is in need of maximum assistance. His or her medical condition is not stable and requires regular monitoring or intervention by a nurse.

II. BACKGROUND AND TRENDS

A. Adult Day Care Provider Inventory

Nationally, a large number of day care centers are part of or are housed in multipurpose centers, such as senior centers, nursing homes, hospitals or churches. Other programs are freestanding. In 1989, The National Council on Aging conducted a census that identified over 2,100 adult day treatment facilities nationwide; 75 percent of these facilities primarily serve the geriatric population. Forty percent of the facilities that primarily serve geriatric population were established after 1984. About 64,000 community-dwelling older people used adult day care in 1989.

There are a total of 24 facilities that provide day treatment to the residents of the District. Five of the programs located in the District, served residents aged 60 and older, five of the programs served developmentally delayed infants aged 0-3 years, and eleven programs served mentally retarded adults, of which two served residents with a dual diagnosis of mental retardation and mental illness. Geriatric day treatment programs located at Community Mental Health Centers North and South programs are not listed, because these programs are designed for older residents with chronic mental illnesses.

B. National and District of Columbia Trends

1. Use

Nationally, users of adult day care generally have minimal limitations in independent functioning. According to a study by W.G. Weissert in 1990, the average age of adult day care participants is almost 78 years with just under 20 percent being older than 84. Most of the adult day care participants are unmarried Caucasian females who live with a relative or another caregiver. More than half of the participants are functionally impaired and almost 40 percent suffer from mental disorders.

In the District of Columbia, based on the 1996 data presented, capacity appears to exceed enrollment for all populations.

The number of people using services among the functionally impaired elderly appears to be only slightly less than capacity. This may be partly due to part-week enrollment by some users, which resulted in enrollment greater than capacity in several facilities. For the developmentally disabled and substance abuse/mentally ill, there appears to be excess capacity relative to use.

2. *Reimbursement*

Currently, Medicaid is the only third-party payer that reimburses for day treatment as a category of service in the District of Columbia. Although Medicare does not recognize day treatment as a category of service, reimbursement is available for outpatient physical, occupational and speech therapy. Private insurers can also be billed for specific medical treatments and therapies when rendered but will not cover general nursing care, case management and other support services, which are components of day treatment.

The 2000 per diem rates of medically supervised day care programs participating in the D.C. Medical Assistance program range from about $39.00 for a mentally retarded adult program to $125.92 for a developmentally delayed infant program.

3. Quality

The National Council On Aging has developed standards for Adult Day Care (ADC) facilities that are based on the range and quality of services provided. ADCs often face the same problem that nursing homes confront in assessing quality. Standards to obtain certification are often intended to ensure a minimally acceptable level of care. Regulation mechanisms such as Licensure and Certification are focused on the environmental standards.

C. Issues Affecting Adult Day Services in the District of Columbia

A 1993 National Institute of Adult Day Care survey of 27 adult day care associations, and subsequent discussions with providers and consumers, identified three overarching policy concerns: financing, service development, and consumer issues: (1) public funding; (2) the limitations in a third party reimbursement; and (3) the lack of federal standards and regulations for the adult day care industry.

1. Public Funding

Although Medicare is an important health care entitlement for older persons, it primarily provides coverage for acute care inpatient and physician services. On the other hand, older people are increasingly suffering from chronic conditions. The greatest health care needs of the elderly may be for services that increase or maintain their functional ability

while managing or improving chronic conditions, which often are not covered by Medicare.

E. Third-Party Reimbursement

As stated earlier, Medicaid is the only third party payer that reimburses for ADC's treatments as a separate category in the District of Columbia. Medicare recognizes reimbursement only for patients that use ADC for outpatient physical, occupational and speech therapy. Private health insurance companies, reimburse only medical treatments and therapies. Private long-term care insurance now generally covers adult day care. Social Services Block Grants and Title III-B of the Older Americans Act Adult also fund day care. The Older Americans Act directs that priority be given to serving those with the greatest economic and social need, with particular attention to low-income minority older persons.

III. NEEDS PROJECTIONS

In order to estimate adult day care spaces needed in the District of Columbia, estimates for the elderly and the developmentally disabled were developed separately. For both, the United States Census Bureau data from 2000 and Census projections was used to project the DC population forward to 2007.

A. Projected Service Needs

1. Aging

For the elderly, using the 1996 enrollment in ADCs for elderly individuals with functional impairment as a percentage of the estimated number of elderly individuals receiving assistance with an ADL or IADL impairment, it was estimated that 2.2 percent of the elderly impaired population in DC used adult day care services in 1996. In order to project demand, this percentage was applied to the estimated elderly population in 2001 and 2007 (**Table 15**). Finally, the necessary capacity to meet the implied demand was calculated assuming an 85 percent occupancy rate for the programs and half of enrollees attending less than full-time.

According to this analysis, the existing supply of MSDC facilities serving elderly users appears adequate to meet demand in 2007.

Table 1.
Method for Estimated Need for Adult Day Care Facility Services

Demand for Services Calculation, 1996

	1996 DC Pop.	Disability Rates 1994 NLTCS Spector, 2000	Pop x Disability Rate	1996 ADC Enrollment	% impaired Using ADC

65-74	41,034	8.0%	3,287		
75-84	25,016	19.8%	4,960		
85+	8,771	51.9%	4,552		
	74,821		12,799	276	2.16%

Demand for Services Calculation, 2000

	1996 DC Pop.	Disability Rates 1994 NLTCS Sector, 2000	Pop x Disability Rate	% impaired Using ADC	Estimated 2000 ADC Demand
65-74	35,951	8.0%	2,880		
75-84	23,979	19.8%	4,754		
85+	8,506	51.9%	4,414		
	68,436		12,049	2.16%	260

Needed Capacity Calculation, 2000

Demand	260
Minimum Occupancy Rate for Programs	85%
Needed Capacity (demand/min. occupancy rate) if All Full-Time	306
Needed Capacity if Half Part-Time (50% full-time (0.5 x 1) plus 50% half-time (0.5 x 0.5) = 75% factor)	230

2. People with Developmental Disabilities

For the developmentally disabled population, the Survey of Income and Program Participation (SIPP) was used to obtain estimates of the national prevalence of mental retardation and developmental disability by age group in the non-institutionalized population.[1] The SIPP defines developmental disabilities as cerebral palsy, autism, or a related condition. The SIPP estimates were applied of the prevalence of MR/DD to the Census projections and summed to derive the projected total MR/DD population.

Using the data on occupancy rates from **Table 1**, estimates were made that at least 150 infants and 845 adults with MR/DD used MSDC services in 1996. The population of ages between 5 and17 was not tracked because most of these individuals are in some sort of educational setting and would not require MSDC services. The number of users was then divided by the estimated size of the District of Columbia infant (age 0 to 4) and adult (age 18 and older) MR/DD populations in 1996 (linear interpolation between the 1990 and the 2000 Census to derive 1996 numbers was used). The results were prevalence rates of 19.3 and 17.9 percent for MSDC use among the infant and adult MR/DD populations, respectively.

Assuming this prevalence rate has remained constant, the estimates of the 2000-2007 MR/DD population were applied to project the number of people demanding MSDC services over this period. The results of these calculations for 2001 and 2007 are presented in **Table 2**.

Table 2
Projections of Number of MR/DD Users of Medically-Supervised Day Care Services 2001 and 2007

Year	Estimated Number of Users[1]			Implied Occupancy Rate (%)[2]		
	Infant	Adult	Total	Infant	Adult	Total
2001	142	819	962	64.1	79.6	76.9
2007	149	854	1,004	67.5	83.1	80.3

Notes: "Infant" refers to ages 0 to 4 and "Adult" refers to ages 18 and older. We obtained the infant prevalence rates by taking the average prevalence of developmental delays for ages 0 to 2 and ages 3 to 5. Totals may not match the sum of columns due to rounding.

[1]The number of users is calculated from Census population estimates multiplied by age-specific MR prevalence rates from the SIPP, then multiplied by the estimated prevalence of ADC use among the MR/DD population (19.3 percent for ages 0 to 4 and 17.9 percent for ages 18 and older).

[2]Calculated as the ratio of the number of individuals demanding services to the number of available "slots," assuming the District of Columbia supply of ADC "slots" remains at its 1996 level of 222 infant and 1029 non-infant slots.

Table 2 shows that demand for MSDC services grows only modestly over the next five years. It has been assumed that each individual uses a full "slot" of services. However, it is very likely that many users of MSDC services are only part-time. Thus, the existing supply of MSDC facilities serving MR/DD users appears adequate to meet demand through 2006.

Both the supply of MSDC and the propensity to use MSDC services were computed from 1996 data. The presence of the new Medicaid Waiver program, which began in 1998, and any future plans the District of Columbia has to expand community-based long term care services, may trigger a positive shift in demand for MSDC services beyond the levels presented above.

Based on the cited data, existing facilities for individuals with MR/DD are sufficient for the needs of this population over the near future.

IV. CRITERIA AND STANDARDS

A. Availability

Availability is defined as the need projection indicating the supply of resources in relation to the need or the demand for resources. The standards of availability for Medically Supervised Day Care Programs (MSDCP) include the following:

(1) The service provided by MSDCP will include assistance with activities of daily

living, medically supervised treatment and therapies indicated in participants' health status, health education and counseling, planned individual and group social activity, physical and educational activities, suited for the needs of participants.

(2) The individual participant's plan of care will outline the provision of meals or snacks in accordance with Medicaid standards of nutrition services, in day treatment programs.

(3) Each MSDCP shall have the minimum capability of providing service to 20 persons on a given day.

(4) MSDCP services for older people, adults who are physically handicapped and residents who are mentally retarded or developmentally disabled should be available in the numbers specified by this plan.

(5) Any MSDCP proposing to expand its daily capacity must have operated with a utilization rate that has met or exceeded 85 percent and must have an actual attendance rate of at least 80 percent for the preceding two quarters. Rates will be determined using the following formulas:

Daily Capacity Rate = total # days participants are scheduled to attend X daily capacity X days in reporting period / daily capacity X days in reporting period

Attendance or Utilization Rate = total # days participants actually attend X daily capacity X days in reporting period / daily capacity X days in reporting period.

B. Accessibility

Accessibility is the measure of the ease of entry of services for the consumer.

The accessibility standards for MSDCP include the following:

(1) All MSDCP facilities must be architecturally designed in conformance with the requirements of Section 504 of the Rehabilitation Act of 1973. Use of the Uniform Federal Accessibility Standards (UFAS) (Appendix A to 41 CRF Section 101 19.6) is recommended. (See 28 CRF Section 42.522,1987 amended).

(2) Each MSDCP shall provide or formally arrange of transportation to and from the program facility, for all participants.

(3) Individuals shall not be denied access to day treatment because of inability to pay;

therefore, each day treatment program shall meet the following requirements:

1. Meet Medicaid and Medicare standards for services that are reimbursable and secure and maintain Medicaid certification.

2. Have written policies governing provision of services without charge for indigent patients including the uncompensated care obligation under D.C. Code, Section 32-305 (a).

3. Establish sliding fee scales based on ability to pay, in accordance with D.C. Code Section 32-305 (a) and;

4. Establish special payment plans for individuals unable to make lump sum payments for services rendered.

5. Programs must be located in areas of close proximity to the target population to minimize transportation time.

6. Facilities must be architecturally designed to meet the needs of the disabled.

C. Continuity

Continuity is the structure, coordination and delivery of services on a continuous basis and in a timely manner. The continuity standards for medically supervised day care programs (MSDCP) include the following:

(1) The MSDCP shall maintain in each participant's plan of care a record of any other health and supportive services that the participant is receiving away from the DTP such as other therapies, homemaker services and other services.

(2) Each MSDCP shall establish written formal referral agreements with providers of social services, home care and other support services.

(3) Each MSDCP shall establish written formal agreements with secondary and tertiary healthcare providers for referrals where appropriate.

D. Quality

Quality is defined as the degree of excellence characterized by levels of technical competence, appropriateness, safety and beneficial impact. The quality standards for MSDCPs are as follows:

The D.C. Medical Assistance Regulations for day treatment programs provides standards for evaluating services which are consistent with the Standards for Adult Day Care developed by the National Institute on Adult Daycare, a unit of the National Council on Aging.

(1) Each MSDCP shall minimally meet the staffing requirements required for Medicaid certification.

(2) Each MSDCP participant shall have a physician authorized written plan of care that is based on the orders of the participant's physician and an assessment by the DTP staff.

(3) The plan of care shall address all program activities, treatment and therapies, that have been determined to meet the needs of the participants. The initial assessment by the DTP staff shall be concluded within seven days after admission.

(4) Each MSDCP shall provide or formally arrange for any service deemed as a necessary component of the participant's plan of care. Provision of such services shall be directly related to the physician authorized written plan of care for the individual.

(5) The MSDCP shall have appropriate written procedures for storing and administering drugs.

The quality of service can be evaluated by reviewing the mix of services offered, the level of experience of the staff and the staff-to-participant ratios. Though a core of essential services is required to meet the participant's plan of care, the provision of additional services distinguishes a day program.

E. Acceptability

Acceptability is defined as the degree of satisfaction of the services to the community and its users. The acceptability standards for MSDCP are as follows:

(1) Upon admission of a participant into the DTP, the provider shall enter into e a written agreement with each participant, or if appropriate, the participant's legal guardian, describing the following:

1. Basic services offered
2. Financial obligation
3. Participant's plan of care

- The MSDCP shall keep the participant or legal guardian apprised of the participant's progress and health status, which includes notifying participants or legal guardians when there is a change in the plan of care such that a treatment service is eliminated or added.

F. Cost

Cost is defined as the total expenses and economic consequence of the provision of services, including provider cost, consumer cost, opportunity costs and societal costs. Costs include:

Day care as an alternative to institutionalization has been viewed as a more appropriate mode of care for some frail older people. The District's Health Plan requires that the financial feasibility of their projects be demonstrated. These projections should be listed by payor source, i.e. Medicare, Medicaid, private, and other sources.

When adult day care is continuous, actual costs of care for a given period represent a potential saving over costs of nursing home care or hospitalization. A study at The Moss Rehabilitation Hospital in Philadelphia study, funded by the Blue Cross Blue Shield Association, revealed per diem costs for its day hospital program, including transportation, were 23 percent less than per diem cost for inpatients and did not include the savings represented by weekends.

For example it is less likely for participants who are not expected to improve to a level of functioning for which a less intensive level of care (e.g. senior centers and social day care) would be adequate. These participants could be maintained in a day health setting until death or institutionalization. In such cases, if a daily rate for living expenses were added to the per diem cost of day care, the actual cost of providing care in the day setting would be greater than providing care in a nursing home.

V. GOALS AND OBJECTIVES

Goal 1: Expand adult day care to meet the needs of the residents of the District of Columbia

Objectives:

1.1 Evaluate the need for expansion of the District's waivers and broaden eligibility requirements in order to meet the most need possible, and thereby avoid institutionalization when possible.

1.2 Coordinate with the District of Columbia, Department of Health, Medical Assistance Administration to ensure that adult day services are accessible and available.

Goal 2: Encourage quality services through data collection, monitoring, training and evaluation of outcomes.

Objectives:

2.1 Design a centralized data collection system to support planning of and enhancements to adult day care services by collecting data to determine the patterns of use, current supply and the trends of utilization of MSDC for the MR/DD population.

2.2.Establish a comprehensive system to monitor the quality of adult day care services in the District of Columbia.

2.3 Determine appropriate quality indicators necessary to properly gauge and track adult day care services.

2.4 Promote additional training of all adult day care workers to enhance care through learning and applying best practices in adult day care.

Goal 3: Develop a more effective inter-agency communication program

Objectives:

3.1: Conduct public dialogue among state agencies, providers, informal caregivers, patients, and other interested parties about adult day care in the District of Columbia.

END OF LIFE CARE

I. INTRODUCTION

Comprehensive end-of-life services are typically provided by hospice and palliative care programs. Providers of end-of-life services have recently begun to make the following distinction between the concept of hospice care and the broader concept of palliative care:[1]

1. Hospice Care, defined as "Services focused on the provision of palliative care or interventions aimed at reducing or alleviating pain and other physical and psychosocial symptoms of terminal illness. With the goal of maximizing the quality of life, hospice services keep the patient comfortable in his or her own home or in a hospice inpatient unit with a home-like environment."

2. Palliative Care, defined as "An intervention that seeks to address not only physical pain, but also emotional, social and spiritual pain to achieve the 'best possible quality of life for patients and their families.' Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness or disease process."

The adjustment to life after the loss of a loved one, can take a long time and a considerable amount of emotional effort, therefore it is often advised that families seek support from the community or other resources. In addition to the above broad services, many hospices offer bereavement support groups.

II. BACKGROUND AND TRENDS

A. End of Life Service Inventory

The District of Columbia's State Health Planning and Development Agency (SHPDA) of the Department of Health has adopted the Medicare guidelines and standards for the review of hospice services. The two hospices in the District of Columbia meet the Medicare criteria for the State Health Plan:

- Hospice Care of the District of Columbia of Columbia, and

- Hospice of Washington.

Table 1 provides specific information about each of these providers.

These agencies provide complementary services to the Hospices:

Georgetown University Hospital Palliative Care Program

- "The Palliative Care Service (PCS)" at Providence Hospital

- The Greater Southeast Community Hospital

- Howard University Hospital

- The Hospital for Sick Children

- William Wendt Center for Loss and Healing – provides counseling to terminally ill individuals and their families.

- Gift of Peace – residential facility operated by the Missionary of Charity; houses some terminally ill persons.

These services are complementary in two ways. First, more patients can receive end-of-life services without the hospice six-month life-expectancy requirement imposed by Medicare. Thus, quality of life may be improved for individuals whose life expectancy is unknown through pain management and other hospice like services. Second, palliative care programs provide assistance in educating eligible patients about the benefits of hospice care, and make referrals as appropriate.

Table 1.
Hospice Providers in the District of Columbia, 2001

	Hospice Care of D.C.	**Hospice of Washington**
Established	1977	1978
Profit Status	Non-profit	Non-profit
Services	- home hospice and in-patient bed services - counseling/ support groups - bereavement counseling, grief and loss program for schools - routine and continuous home care - after hours nursing staff - general inpatient and respite care - transitional home health - pain management, - Physical Therapy - Nutrition	- bereavement counseling - home hospice - routine and continuous - 9 bed inpatient unit - respite care - pain and symptom management - bereavement programs for schools and children - counseling and support groups - after hours nursing care
Providers	Dr., Nurses, Social Workers, Home Health Aids, Physical Therapists, counselors, chaplain	Dr., Nurses, Social workers, Home Health Aides, Physical Therapists, Volunteers, Counselors and Chaplain
Client Capacity	50-70 pts/day	35-45 pts/day 500+/year

Geographic Origin	1/3 NW, 1/3, NE, 1/3 SE/SW	Throughout D.C.
Age	Treat 18+, however most patients are elderly 65+	18+, but mostly elderly 65+
Socioeconomic Status	All levels	All levels
Ethnicity	Varied - 62% black, 34% white, 4% other	Varied
Diagnoses	Ca, Cardiovascular and Pulmonary, Dementia HIV/AIDS, all serious illnesses	Ca, Cerebro vascular and renal, dementia, pulmonary, AIDS, Cardiac, and all serious illnesses
Payment Options	Mcare, Mcaid, HMO, Private Insurance	Mcare- 65%, Mcaid- 5%, HMO- 30%
Pro-bono Services	YES - they do not turn any patients away	YES
Regulation	Medicare, Medicaid, JCAHO	Medicare, Medicaid, DCRA, JCAHO
Healthcare Facility Network	Various nursing homes, Hospice of N. VA, All D.C. Hospitals including the VA	Contract with VNA, Hospice Alliance and other nursing homes in the area. Hospitals, home care agencies and other hospices in VA/MD/DC

B. National and District of Columbia Trends

1. Patient Demographics

The 1996 National Home and Hospice Care Survey provided information about the characteristics of hospice users in the U.S. Nationally, 78 percent of hospice patients were 65 years of age and over. Ten percent were between the ages of 55 to 64; approximately 5 percent were between 45 to 54 years of age and 7 percent were less than 45 years of age. Fifty-five percent of the patients were female. Eighty-four percent were white, 8 percent were black, and 7 percent were of unknown race. Fifty percent of the patients had cancer diagnoses, 17 percent had diseases of the circulatory system, three percent had metabolic diseases, three percent had nerve disorders, four percent had diseases of the nervous system and sense organs, and six percent had diseases of the respiratory system.

The District of Columbia is making preparations to collect more accurate data on the utilization or characteristics of hospices users in the District of Columbia. However, it is the view of the SHPDA that End-of-Life services in the District of Columbia are evolving and expanding along two strategic approaches.

The first approach is the provision of hospice services through the traditional Medicare hospice paradigm, to be in compliance with Medicare guidelines and standards. The current Medicare hospice benefit allows for services to be provided beyond the six-month

limitation through a 60-day certification period, after the first two 90-day election periods.

The second approach is the provision of end-of-life services, where emphasis is placed upon pain management and palliative care for the terminally ill. These pain management and palliative care programs allow for services to be extended beyond the Medicare six-month limitation. Both approaches working together will eventually provide services for two distinct populations, the terminally ill with less than six months to live and the chronically ill who require palliation to remain at their limited functional level.

2. Reimbursement

Medicare and Medicaid are both important sources of payment for hospice services. Medicare provides hospice benefits to Medicare beneficiaries nationwide who qualify for the benefit. Forty-three states provided hospice benefits through Medicaid as of 1999.

Medicare beneficiaries, who are certified by a physician as terminally ill, with a life expectancy of six months or less, can elect hospice coverage. Patients electing the Medicare Hospice benefit agree to waive standard Medicare benefits for curative treatment of their terminal illness, and instead receive non-curative care and support. Medicare Hospice providers must provide a "core" of services including nursing care, medical social services, physician services, and counseling. The hospice must also retain professional management responsibility for all non-core services contracted out to other providers.

The current rate as of the year 2000, in the District of Columbia is $109.30. Hospices are paid for continuous home care when home care is provided for more than eight hours, up to a maximum of twenty-four hours. Medicare currently pays $637.92 (or $26.58/hour) for this type of care in the District of Columbia. The inpatient respite care rate of $109.79 is paid when the patient is receiving respite care in an approved inpatient facility. The patient's stay cannot exceed more than five days at a time. Payment for any subsequent days would be made at the routine home care rate. The general inpatient rate of $483.05 is paid when the patient receives inpatient care and cannot exceed 20% of the total hospice days.

3. Quality

Although some geographic areas are still under-served, hospices are operating nationwide. According to the National Hospice and Palliative Care Organization (NHPCO), as of 1999, forty-four states required licensure for hospice services.

The District of Columbia currently requires hospices to be Medicare/Medicaid certified. The District of Columbia City Council passed D.C. Law 5-48 the "Health-Care and Community Residence Facility, Hospice and Home Care Licensure Act in 1983".

Through its Standards and Accreditation Committee, NHPCO has established benchmark guidelines for establishing quality hospice services nationally. Many of the guideline statements are reflected in the requirements for participating in the Medicare Hospice Benefits Program. In addition, the NHPCO has published *Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases* to assist hospices and physicians in certifying non-cancer patients as having fewer than six months to live and therefore qualifying for the Medicare Hospice benefit.

C. Issues Affecting End of Life Services in the District of Columbia

- Education and Communication related to End of Life Services;
- Limitations of the Medicare Hospice Benefit; and,
- Shortage of utilization data and epidemiological information on patients, providers and EOL services in the District of Columbia.

III. PROJECTIONS

The need for hospice services is based upon current user patterns. These results must be interpreted with caution because hospices, while critically important as providers of care at the end of life, do not constitute the entire delivery system for end of life services.

As shown in **Table 1**, there are two Medicare/Medicaid certified hospices in the District of Columbia: Hospice Care of DC, and Hospice of Washington. Daily and annual client load data was provided through telephone interviews. An estimate was then made that these two providers collectively serve about 1,500 per year.[1]

At least two factors play major roles in the projection of hospice need in the District of Columbia through 2006. First, while the rate of hospice use should reasonably be expected to be a function of the death rate, it is not clear that historical death rates in the District of Columbia can be used to project death rates through the projection period.

In particular, deaths from AIDS dropped dramatically between 1995 and 1999 as a result of new anti-retroviral drug therapies. Researchers do not know, however, to what extent these death rate declines are permanent. For the purposes of this needs estimate, we assume that recent hospice use rates by age group, which reflect current death rates from AIDS, will remain stable. This assumption becomes more tenuous in the out-years of the projection.

Second, the National Hospice and Palliative Care Organization reports that, hospice admissions nationwide jumped markedly from 1998 to 1999, from 540,000 to about 700,000. Thus, using historical (including current) use rates to estimate service needs five years from now could inappropriately restrict development of a rapidly growing area of service delivery. Nevertheless, for the purposes of this needs estimate, we assume we assumed that hospice use rates by age group would remain constant from 2000 to 2007. Any change in the overall rate of hospice use in the District of Columbia between 2001 and 2007 would be the result of changes in the age distribution of District residents.

National hospice use rates by age group (under 65, 65-74, 75-84, and 85+) derived from the 1995 National Home and Hospice Care Survey were used. The resulting total number of hospice users was then calibrated to the actual number of hospice users in the District of Columbia in 2000, to ensure that the most current utilization of hospice services is reflected. Average length of use by age group was used to calculate the number of days of hospice care demanded based on the projected number of hospice users. District population projections were derived by applying 2000-2006 projected growth rates by age and sex, published in 1997, to recently available DC population data by age and sex from Census 2000. The results are shown in **Table 2.**

According to this analysis, – the demand for hospice services will remain stable through 2007. Therefore, the current complement of hospice providers is sufficient to meet the District of Columbia's needs throughout this period.

Table 2. Projected Need for Services of Medicare/Medicaid Certified Hospices in the District of Columbia, 2001-2007

	2001	**2007**
Age 0-64		
DC population	501,625	526,672
Est. # users	457	480
Est. Days	26,552	27,878
Age 65-74		
DC population	35,051	33,399
Est. # users	322	307
Est. Days	14,473	13,792
Age 75-84		
DC population	24,625	23,483
Est. # users	418	399
Est. Days	38,084	36,317
Age 85+		
DC population	8,933	9,506
Est. # users	286	305
Est. Days	15,437	16,427
Total		
DC population	570,234	593,059

Est. # users	1,483	1,490
Est. Days	94,546	94,414

Source: The Lewin Group analysis of data from: telephone conversations with the three Medicare/Medicaid certified hospices in the District of Columbia ; Lewin tabulations of data from the 1995 National Home and Hospice Care Survey; 2000 DC population from U.S. Bureau of the Census; 2007 DC population projection provided by SHPDA.

IV. CRITERIA AND STANDARDS

SHPDA, in conjunction with the D.C. Hospital Association - Partnership to Improve Care for the Dying, is currently developing a data collection initiative in order to generate epidemiological data on EOL services in the District of Columbia. The data will be used to determine the availability, accessibility, continuity, quality, acceptability and cost of EOL services throughout the city.

V. GOALS AND OBJECTIVES

The guiding vision for establishing sustainable End-of-Life services for the end-of-life phase of terminally ill District residents rests upon ensuring access to culturally sensitive, quality health and related human services.

Goal 1: Ensure that every resident of the District of Columbia of Columbia who is living with eventually fatal chronic illness can receive reliable, appropriate care, throughout the rest of his or her life.

Objectives:

1.1: Develop an effective program for continuing public dialogue on improving end-of-life care in the District of Columbia.

1.2 Establish a leadership group to guide improvements in end-of-life care in the city. 1.3 Improve the following three aspects of end-of-life care in the District of Columbia: (1) more efficient and capable home/hospice care; (2) more support for dying persons living in nursing homes and other senior housing; (3) more uniform policies across all care-giving entities about advance care planning and symptom relief guidelines; and (4) more training in best models and practices in end of life care for all health care disciplines in all settings.

1.3 Design a program to improve data collection to support planning of and improvements to end-of-life services.

APPENDICES

APPENDIX A

Draft Licensure Categories and Definitions for Home Health Services

The draft licensure regulations include the following home health service categories and definitions:

1. Clinical Laboratory Services/Special Monitoring Services: Support services needed by providers to help monitor and evaluate the individual's condition. Clinical laboratory services include routine biochemistry, hematology, immunology and microbiology. Special monitoring services supply information for monitoring purposes, and include, but are not limited to, diagnostic x-ray, electrocardiograms, apnea monitor, and emergency response systems.

2. Counseling Services: Psychosocial counseling, including supportive and other therapeutic intervention, to clients/patients and/or their families related to illness, injury, disability and treatment alternatives, and coping with adjustments in their lives due to illness, injury or disability. Peer counseling is not included.

3. Dialysis: Provision of services, monitoring and instruction related to artificial kidney treatment. Includes home dialysis, home hemodialysis training, continuous ambulatory peritoneal dialysis and intermittent peritoneal dialysis.

4. Home Care Equipment and Supplies: Provision, maintenance, demonstration of use and operation, storage and/or repair of special equipment or supplies needed by individuals to maintain their highest level of functioning.

5. Nutritional Services: Assessing the nutritional needs of individuals and families; educating them on how to meet their nutritional needs, including special requirements related to illness or injury; and guiding them in purchase, handling and preparation of food. Home delivered meals are not included in this category of service.

6. Occupational Therapy: Treatment using task oriented activities to prevent, correct or ameliorate physical or emotional deficits of the individual, with special emphasis on the developmental and functional skills needed throughout life.

7. Other Skilled Health Care Services: Provision, instruction and monitoring of skilled health care services not listed elsewhere. This addresses all aspects of nursing care, including patient assessment, case management, supervision of home health aides, coordination with physicians, etc.

8. Parenteral Services: Refers to the administration of substances using routes that are not part of the digestive system. This includes subcutaneous, intravenous and intramuscular pathways.

9. Personal Care Services: Provision of care for the maintenance of one's body, including toileting, dressing, bathing, hair and nail care, helping with eating and other hands-on activities.

10. Pharmacotherapy: Provision, administration and monitoring of medicinal substances taken by mouth, injection or other means, either by prescription or over-the-counter.

11. Physical Therapy: Treatment of human disability, injury or disease by supervised therapeutic procedures embracing the specific scientific application of physical measures to secure the functional rehabilitation and/or maintenance of the human body.

12. Respiratory Therapy: Provision of services, monitoring and instruction designed to identify respiratory abnormalities and to restore them to normal.

13. Service Management: Intensive management and coordination of multiple services delivered to the client/ patient who has complex service needs and/or whose situation is unstable and requires considerable time to manage.

14. Speech Pathology and Audiology Services: Identification, assessment and treatment of individuals with speech, language or hearing disorders.

15. Status Evaluation: Initial comprehensive and specialized assessments and periodic examinations and evaluations of an individual related to a therapeutic/supportive regimen, including but not limited to any or all of the following areas: nutritional, medical, nursing, dental, Psychosocial and Pharmacotherapy.

Appendix B

Administrative Oversight

At the federal level, the Centers for Medicare and Medicaid Services (CMS) is responsible for administering the Medicare and Medicaid programs. CMS works to assure that these programs are properly run by its contractors and state agencies; establishes policies for paying health care providers; conducts research on the effectiveness of various methods of health care management, treatment, and financing; and assesses the quality of health care facilities and services and taking enforcement actions as appropriate. CMS has a particular focus on improving the quality of health care provided to Medicare and Medicaid beneficiaries by developing and enforcing standards through surveillance, measuring and improving outcomes of care, educating health care providers about quality improvement opportunities and educating beneficiaries to make good health care choices.[31]

The key government agencies involved in the delivery of long-term care services at the local level include: the Department of Health, including the Medical Assistance Administration (Office on Disabilities and Aging), Health Regulation Administration, HIV/AIDS Administration, Office of the General Counsel, and Office of Policy Management; the Department of Human Services, including the Office on Aging, Rehabilitative Services Administration, Mental Retardation/Developmental Disabilities Administration, Adult Protective Services, and Income Maintenance Administration; the Department of Mental Health; the DC Housing Authority; the Office of Corporation Counsel; and the Office of Chief Technology Officer.

The Health Regulation Administration (HRA) administers all District and Federal laws and regulations governing the licensing certification and registration of health related professionals, health care and human service facilities and establishments. It licenses community residence facilities, ICFs/MR, hospice, and nursing facilities and certifies nursing facilities and home health agencies under Medicare and Medicaid participation requirements. It acts as the District of Columbia's primary quality assurance authority. The Health Services Division is responsible for conducting annual surveys of nursing facilities in the District of Columbia, as well as investigating complaints regarding these facilities, to determine compliance with federal and district regulations. Results are made available to the public via the Freedom of Information Act.[32]

The Medical Assistance Administration (MAA) is the state agency responsible for administrating Title XIX of the Social Security Act (the District of Columbia's Medical

[31] Taken from the CMS website at www.hcfa.gov

[32] Taken from the DC Health website at www.dchealth.com

Assistance program), as well the Medical Charities program, and other health care financing initiatives of the District of Columbia. MAA develops a comprehensive plan for financing health care for the District of Columbia's uninsured and indigent residents in support of the health care goals set by the Mayor an the Department of Health. MAA is responsible for developing eligibility, service coverage, service delivery and reimbursement policies for the District of Columbia's health care financing programs.[33] Medicaid covers Medicare premiums for low-income beneficiaries as well as certain acute care services not covered by Medicare.[34]

The Office on Disabilities and Aging (ODA) within MAA is responsible for the management and operation of nursing facilities, ICF/MR facilities, home health, personal care attendants, day/active treatment, three Medicaid waivers (MR/DD Waiver, Elderly Waiver, HIV/AIDS Waiver) and hospice care.

These programs and services support health and social services for adults age 65 and over; persons under age 65 with disabilities; persons with mental retardation and/or developmental disabilities; and persons with AIDS.

The HIV/AIDS Administration (HAA) provides funding for the majority of the HIV/AIDS services in the District of Columbia. The services include AIDS Statistical Updates; HIV Counseling & Testing; HIV Prevention and Awareness Session; case management; AIDS drug assistance; substance abuse treatment; complementary therapies; capacity building for community based organizations; housing; primary medical care; nutritional counseling; emergency drug assistance; rental assistance; utility assistance; food bank; home delivered meals; discharge planning; support groups; professional mental health counseling; childcare/baby sitting; dental care; transportation assistance; crisis intervention; interpreter services; legal services; home health services; hospice care; respite care; day treatment; vocational services; and permanency planning. More information about these services can be found in Chapter 13.

The District of Columbia's Office on Aging is the single State and Area Agency on Aging planning agency as authorized under the federal Older Americans Act. It provides a range of services to residents who are 60 years of age and older. Services are provided through a partnership with the Senior Service Network, an organization comprised of 30 community-based organizations funded by the Office on Aging. Services range from health promotion to nursing facility care and include home health, homemaker, home delivered meals, day care, geriatric day treatment, respite care, transportation and escort, friendly visiting, information and assistance, counseling, congregate meals, recreation and social activities at senior centers.

[33] These functions were recently split between MAA and the health Care Safety Net Administration (HCSNA). HCSNA manages the new Alliance program.

[34] Ibid.

The Adult Protective Services (APS) branch of the Department of Human Services works to end or remedy neglect, abuse and exploitation of vulnerable adults. Most APS caseloads consist of adults over the age of 60. However, an increasing number of younger disabled adults are being cared for by APS.

Under the federal Older Americans Act, every state, including the District of Columbia, is required to operate a Long Term Care Ombudsman Program. The ombudsman plays an important role for residents in long-term care facilities by promoting quality of care for residents of nursing facilities and alternative care settings. The primary role of the ombudsman is to act as an advocate for the residents through investigating and resolving complaints made by or on behalf of the residents.

The Mental Retardation and Developmental Disabilities Administration (MRDDA) provides services and supports to maximize the quality of life for persons with mental retardation or other developmental disabilities. MRDDA promotes life-planning strategies and for eligible District residents, ensures that, practical living skills, vocational training, and regular or sheltered employment is available. MRDDA administers the MR/DD waiver.[35]

Legislation in April 2001 created the Department of Mental Health, which is primarily responsible for regulating the District of Columbia's community-based network of mental health care, but it will also continue to provide some mental health services. The new agency aims to create clear performance goals to oversee the certification and monitoring of all non-hospital mental health facilities to improve service to consumers within the mental health system.[6]

The Rehabilitation Services Administration (RSA) assists persons with disabilities in becoming employed and/or to live independently in the home and community. RSA works with communities, businesses and organizations in their efforts to accommodate persons with disabilities and afford them opportunities for integrated employment in the mainstream of society. RSA also administers the Social Security Disability Determination Program that adjudicates claims for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).[36]

The Income Maintenance Administration (IMA) is responsible for the implementation of the District of Columbia's welfare reform legislation and meeting the federal mandates under the Personal Responsibility and Work Opportunity Act of 1996. IMA makes determinations of eligibility and the amount of assistance for TANF, Medical Assistance,

[35] Taken from the Department of Human Services website at www.dhs.washington.dc.us

[6] A plan update chapter on Behavioral Health Services will be developed in FY02.

[36] Ibid.

and Food Stamps. Within the IMA, the Bureau of Program Operations has oversight of the day-to-day operations for IMA's eight decentralized service centers that coordinate certification and re-certification of benefits. The Bureau of Management Systems monitors the administration of benefits including quality assurance, eligibility review, payment accuracy, and investigations of alleged fraud. The Bureau also carries out a wide variety of federal and local mandates and court orders.

The District of Columbia Housing Authority manages affordable housing in the District of Columbia and seeks to achieve the highest and best use of that housing for people of low and moderate income through the promotion of economic development and self-sufficiency opportunities and the facilitation of other supportive services.

Appendix C:
Summary Resource Inventory – District Hospice and Palliative Care Agencies

Georgetown University Hospital, Lombardi Cancer Center
3900 Reservoir Road, NW
Washington, DC 20007
202-784-4000

Hospice Care of D.C.
1331 H St., NW
Washington, DC 20005
202-347-1700

Hospice of Washington
3720 Upton Street, NW
Washington, DC 20016
202-966-3720

MedStar Visiting Nursing Association
6000 New Hampshire Avenue, N E
Washington, DC 20011
202-882-6988

Providence Hospital Palliative Care Center
1150-1160 Varnum St., NE
Washington, DC 20017
202-269-7000

GLOSSARY

ACTIVITIES OF DAILY LIVING (ADLs): The ability to get in and out of bed, bathe, dress, eat and take medication prescribed for self administration and to engage in toileting.

ALZHEIMER'S DISEASE: A form of pre-senile dementia that usually occurs between the ages of 40 and 60. The disease is characterized by progressive, irreversible loss of memory, deterioration of intellectual functions, apathy, speech disturbances and disorientation.

BED-TO-POPULATION RATIO: The number of beds certified for a specific health care service to every 1,000 persons in the group intended as the primary users of the service.

BEREAVEMENT: The period of time during which a person experiences, responds physically and emotionally to, and adjusts to, the loss by death of another person.

CASE-MIX PAYMENTS: A reimbursement system based on the principle that payment for services should take into account the illness level of the resident. Each resident is assessed at some standard time interval and receives services appropriate to those needs identified.

CASE MANAGEMENT: A collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality cost effective outcomes.

COMMUNITY RESIDENCE FACILITY (CRF): A facility providing safe, hygienic sheltered living arrangements for one or more individuals. These individuals should not be related by blood or marriage to the residence directed and should be ambulatory and able to perform the activities of daily living with minimal assistance.

COUNSELING: A relationship in which a person endeavors to help another understand and solve his or her adjustment problems.

DECUBITUS ULCER: An ulcer or break in the surface of the skin usually resulting from pressure from a bed or a chair.

DEMENTIA: Irrecoverable deteriorative mental state with absence or reduction of intellectual faculties due to organic brain disease.

DISEASE MANAGEMENT: A system of coordinated healthcare interventions and communications for populations with conditions in which patient self-care efforts are significant. Disease management supports the physician or practitioner/patient relationship and plan of care, emphasizes prevention of exacerbations and complications and evaluates clinical, humanistic, economic outcomes on an ongoing basis.

END OF LIFE CARE: Pain management, palliative care and hospice services for individuals with a serious chronic illness who will die.

HARD TO PLACE PATIENTS: Patients requiring highly specialized equipment, needing extensive monitoring or whose condition is considered unstable. The following patients are included in this designation:

(1) Stable Respirator Patients

(2) Chronic Unstable Conditions

(3) Patients with Severe Behavior Disturbances

HOME CARE SERVICES: Formally organized services provided to hospice patient/family in the home.

HOME HEALTH AIDE/HOMEMAKER SERVICES: Services that are necessary for maintaining the patient at home. Services may include assistance in the activities of daily living, e.g. helping with bathing, assistance in and out of bed, and maintenance for a safe and healthy home environment, e.g. changing the bed doing personal laundry.

HOSPICE CARE SERVICES: Focus on the provision of palliative care or interventions aimed at reducing or alleviating pain and other physical and psychosocial symptoms of terminal illness. With the goal of maximizing the quality of life, hospice services keep the patient comfortable in his or her own home or in a hospice inpatient unit with a home-like environment.

INPATIENT SERVICES: Formally organized services provided to the hospice patient/family in an inpatient setting which may be a freestanding hospice or hospital/nursing-home-based hospice units.

INTERDISCIPLINARY TEAM: a group of individuals from various professions and disciplines who closely interact in the provision of care to the terminal, end of life patient/family.

INTERMEDIATE CARE FACILITY FOR THE MENTALLY RETARDED (ICF/MR): State licensed facilities that provide 24-hour care and supervision to persons with MR/DD who can benefit from active treatment. Generally health, social, personal care, and related supportive services are provided in a protective setting to meet the needs of functionally and/or mentally impaired individuals.

INTERMEDIATE CARE NURSING FACILITY (ICNF): A facility, or distinct part of a facility, primarily engaged in providing intermediate care that is largely custodial, rather than medical, in nature. Contrast to skilled nursing facility (SNF).

LEVEL OF CARE: Refers to the amount of medical care and assistance with activities of daily living needed by individuals in a group. Traditionally, level of care refers to the skilled nursing or intermediate care patients.

LICENSED BEDS: The number of beds in a designated care category in an institution that have received licensure from District of Columbia Department of Consumer and Regulatory Affairs.

LIFE CARE/CONTINUING CARE COMMUNITIES: Communities that provide a range of services for elderly residents, including homes or apartments for independent living, home care services, and sometimes nursing home services. A payment of an initial membership fee for all types of health and social services for the rest of his/her life.

MR/DD: MENTALLY RETARDED/ DEVELOPMENTALLY DISABLED:

Mentally Retarded: Individual with subnormal intellectual functioning which originates during the developmental period and is associated with impairment of one or more of the following: (1) maturation, (2) learning, (3) social adjustment.

Developmentally Disabled: Disorder in which there is a delay in development based on that expected for a given age level or stage of development. These impairments or disabilities originate before age 18, may be expected to continue indefinitely, and constitute a substantial impairment.[1]

OPERATING BEDS: The number of beds in an institution that are licensed in a given category which are being used or able to be used by patients.

PALLIATIVE CARE: Intervention that seeks to address not only physical pain, but also emotional, social, and spiritual pain to achieve the "best possible quality of life for patients and their families." Palliative care extends the principles of hospice care

to a broader population that could benefit from receiving this type of care earlier in their illness or disease process.[1]

PRIMARY CARE PERSON: That member of the family or personal friend who is designated by the patient and the hospice care team as the leading giver of care to the patient at home.

PROFESSIONAL STANDARDS REVIEW ORGANIZATION (PSRO): A physician or professional medical organization that enter into an agreement with the U.S. Department of Health and Human Services to assume the responsibility for the review of the quality and appropriateness of services covered by Medicare or Medicaid.

RESOURCE UTILIZATION GROUPS (RUGs): A standard method of grouping nursing home residents in accordance with the services they require.

SKILLED NURSING FACILITY (SNF): A facility, or a distinct part of a facility primarily engaged in providing to in-patients continuous professional nursing coverage and related health services under the direct supervision of physicals. Skilled care facilities are solely limited to those facilities classified as nursing homes, convalescent homes, and extended care facilities which provide twenty-four (24) hour professional nursing services under direct supervision of a full-time Medical Director or principle physician.

SPEND-DOWN: A method by which an individual establishes Medicaid eligibility by reducing gross income through incurring medical expenses until net income (after medical expenses) is minimal.

SWING BEDS: Nursing facility beds that are designated for use as either skilled nursing or intermediate care depending on the demand for a specific type.

REFERENCES

Braddock, D., R. Hemp, S. Parish, M.C. Rizzolo (2000). *The State of the States in Developmental Disabilities: 2000 Study Summary*. Chicago: Dept. of Disability and Human Development, University of Illinois at Chicago.

Carelli, R. (1999). Court Mandates Homelike Settings for Mentally Ill. *The Associated Press*

CMS (2000a). *Report to Congress: Appropriateness of Minimum Nurse Staffing Ratios in Nursing Homes*. http://www.hcfa.gov/medicaid/reports/rp700hmp.htm

CMS (2000b). *Report to Congress: Interim Report on NH Quality of Care and Implementation of the Nursing Home Initiative*. http://www.hcfa.gov/medicaid/reports/rtcfall0.htm

Harrington, C., J. Swan, V. Wellin, W.Clemena, H. Carrillo. *1998 State Data Book on LTC Programs and Market Characteristics*. Baltimore, MD: The Health Care Financing Administration, 1999.

HCIA-Sachs, LLC and Arthur Andersen, LLP (2001). *The Guide to the Nursing Home Industry, 2001*. Baltimore, MD: HCIA-Sachs, LLC.

Lakin, K. C. and Hayden, M. (1999). *The Policy Foundation of Medicaid Home and Community-Based Services for Persons with Mental Retardation and Developmental Disabilities*. Unpublished Manuscript.

Larson, S.A., & Lakin, K.C. (1989). "Deinstitutionalization of persons with mental retardation: Behavioral outcomes." *Journal of the Association for Persons with Severe Handicaps*, 14(4): 324-332.

Mollica. R. (2000, July). State Assisted Living Policy: 2000. National Academy for State Health Policy. Prepared under a grant from the Retirement Research Foundation.

Wiener, J.M. and Stevenson, D.G. (1999). Long-term Care for the Elderly in the District of Columbia of Columbia: Issues and prospects. The Urban Institute.

Wunderlich, G. S. and Kohler, P. O. Eds (2001). Improving the Quality of Long-Term Care. Institute of Medicine. Washington, DC: National Academy Press.